Department
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Pensions

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Social Research

The Impact of Fluctuating Health Conditions on Assessment

Improving the understanding of fluctuating health conditions and their impacts on the disability community and on the assessment process.

October 2024

DWP research report no. RR 1057.

A report of research carried out by Basis Social on behalf of the Department for Work and Pensions.

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Executive summary

This report provides findings from a mixed-method (quantitative and qualitative) research study with people with disabilities and fluctuating health conditions conducted across the UK from mid-January to late April 2023. This research included a survey of 297 people, a 4-week diary study with 46 participants and in-depth interviews with 49 participants.

The Department for Work and Pensions (hereafter DWP) wanted to develop an improved evidence base and understanding of applicant experiences of fluctuating conditions. This research set out to understand the best way, within the DWP process disability application and assessment, to capture the impact of conditions which fluctuate.

Participants in this study had a broad range of fluctuating underlying conditions that disabled them in differing ways and to differing degrees of severity and frequency. The underlying conditions and timing of initial onset also varied. Many had multiple co-occurring conditions.

The research highlighted the complexity of living with conditions that fluctuate over time and the impact this has on an individual’s life. Respondents emphasised the difficulty in describing fluctuations - their physical, emotional, and cognitive outcomes, and impacts of these on daily life - to third parties such as the DWP.

Through research insights we identified an ongoing cycle of fluctuation with five constituent elements. This framework for understanding fluctuation may be helpful in staging conversations with benefit applicants to support a better understanding of the nature and impacts of life with a fluctuating condition.

Those five elements were:

1. **Underlying condition(s):** the foundation that causes differing degrees of predictability and manageability of a condition.
2. **Trigger**: A trigger can bring on, worsen, or change a condition at a certain point in time.
3. **Manage**: Actions that are taken to both prevent fluctuations or flare ups and/or reduce outcomes.
4. **Outcome**: The level and duration of a variance in physical, cognitive, and emotional ability.
5. **Impacts**: How the variance in physical, cognitive, and emotional ability influence an individual’s current and future ability to undertake daily living tasks and responsibilities such as work commitments or social activities.

Through the research we identified four potential areas in which the application and assessment process for disability benefits could be strengthened.

These included:

1. Improving the questions asked of applicants within the application and assessment process accounting for variability, triggers and actions taken to manage conditions.
2. Providing greater flexibility in the application and assessment process including the timing and format for applicants to provide evidence of the impact of their conditions.
3. Ensuring health disability assessors receive training on predictability, manageability, and varying fluctuation cycles experienced by many applicants.
4. Providing support and guidance to help claimants describe the impact of fluctuating conditions through the process.

Participants involved in the qualitative research also provided feedback on three potential initiatives designed to improve the disability application and assessment process: a health impact record, direct supply of medical evidence by a GP or the NHS, and involvement of specific assessors trained to better match an applicant's main health condition. These ideas were largely viewed positively, but each came with administration provisos.

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This project was conducted by disability research specialists Open Inclusion in partnership with independent researchers Basis Social.

Participants provided a wide range of valuable insights to work with through their survey, diary and interview responses. We thank them for their time and willingness to do so.

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Glossary of terms

Assessment

When referring to assessment/s in this report, we are referring to the Department for Work and Pensions' assessment of applicants for disability benefits programmes that the department administers.

Cognitive capability

Cognitive capability and challenges relate to how people think. These include what information people receive and how they receive this, as well as how they process, problem solve, or remember. It can influence how and what people understand, their decisions, interpersonal connection, and communication approaches.

Dexterity capability

Dexterity capability and challenges may relate to limitations in arm, wrist, hand or finger function or strength. Dexterity impairments include tremors and control challenges, significant size, shape, or strength difference, muscular or nerve limitations. People with limited dexterity may use assistive technologies such as prosthetics, supports such as wrist braces or adaptive tools.

Duration of change

Duration of change is how long a flare up or episode persists. For example, new or recurring symptoms may persist for minutes or hours, days, weeks or longer.

Flare Up / Episode

A flare up / episode is when one or more symptoms are experienced or experienced more severely by the individual.

Fluctuating condition

A fluctuating condition is an underlying condition that generates variable symptoms and functional effects across time. These may include reduced physical, cognitive and/or emotional capability.

Frequency of change

Frequency of change is how often a new flare up or episode occurs. For example, significant changes in symptoms may occur daily, weekly, monthly, or seasonally.

Health Transformation Programme (HTP)

The Health Transformation Programme (HTP) is a Department for Work and Pensions (DWP) programme of work looking to understand and improve the efficiency and outcomes of the application and assessment process for disabled people and those with long term health conditions applying for DWP managed benefits in the UK.

Long term health condition

Long term health conditions are illnesses, diseases or disorders that impact an individual and require personal management over a long period. They may change over time in symptoms, severity, predictability, manageability, or degree of fluctuation; however, they persist for more than a year.

Mental health

Mental health incorporates people's emotional, psychological, and social well-being. It can be impacted by emotional energy and resilience, psychological safety, social position and stresses, how people relate to others and how they relate to us.

Mobility capability

Mobility capability and challenges relate to ambulatory stamina and capability. Mobility impairments include functional nerve or muscular limitation, limb loss, significant size or strength difference, balance challenges or chronic pain. People with mobility challenges may use assistive technologies such as prosthetics, stability canes or frames, mobility scooters or wheelchairs.

Personal Independence Payment (PIP)

Personal Independence Payment is a UK Government benefit scheme covering England and Wales. It is designed to help with extra living costs for people with long-term conditions or disabilities who qualify and who are aged between 16 and the state pension age.

Self-care

Self-care is making decisions and taking proactive steps to better manage personal physical, emotional, or cognitive resources and outcomes.

Sensory capability

Sensory capability and challenges relate to how people receive sensory inputs including sound, visual stimuli, and touch. Sight loss and hearing loss can disable people through reduced sensory inputs. Autism and other neurological conditions can disable people through increased sensitivity to sensory inputs.

Trigger

A trigger is something that can bring on, worsen, or change the impacts of a condition. It can include environmental factors such as weather, personal choices such as diet or rest, and other external factors such as stress and anxiety. Triggers may be known or unknown.

Underlying condition

We define an underlying condition as any diagnosed or diagnosable medical condition or disability that can generate negative health effects, symptoms, or reduced capabilities. It does not include any demographic factors such as age, ethnicity, or gender. We have used 'condition' and 'underlying condition' synonymously.

Abbreviations

DWP – Department for Work and Pensions
HTP – Health Transformation Programme
PIP – Personal Independence Payment
ADHD – attention deficit hyperactivity disorder
PTSD – post-traumatic stress disorder

Summary

Living with a fluctuating condition can make the application and assessment process for DWP disability benefits more of a challenge.

To better evidence and understand the difficulties people with fluctuating conditions face when applying for benefits, Open Inclusion and Basis Social were commissioned by DWP to conduct three sequential stages of quantitative and qualitative research which form the basis for this report.

The research included an,

- **Online survey:** Completed by 297 individuals. Each self-identified as having one or more fluctuating health conditions that impacted at least one of seven specified daily living activities (Household, Work, Social, Leisure, Education/learning, Finance or Travel)
- **4-week diary study**: Completed by 46 participants across a 4-week period[1]
- **In-depth interviews**: Completed with 49 participants who had been part of the diary study[2]

The research was conducted between January and April 2023 with individuals self-identifying as having fluctuating conditions that impacted at least one aspect of life. It was designed to provide a deeper understanding of fluctuating conditions, evidenced by a range of individuals with different underlying conditions and experiences of fluctuations. The research approaches were specifically designed to be disability inclusive, adapted to meet the needs of a wide range of participants.

The insights from the research have highlighted a range of ways to progress the design, development, and delivery of future DWP disability application and assessment processes and capabilities. Such changes could support claimants with fluctuating conditions to better describe their situation so they may be more accurately and fairly assessed relative to those with conditions that do not significantly fluctuate.

Fluctuating conditions

The research highlighted how living with fluctuating conditions is complex, requiring individuals to manage ongoing changes in capability to undertake different activities across time. Which activities an individual undertakes can have implications for themselves and those around them (e.g., using energy for one activity can reduce or rule out someone’s capacity to undertake another activity).

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[1] 804 individual diary entries were made during the diary study through a range of accessible and suitable formats. These included a baseline description of physical and mental health, weekly round ups and updates when significant changes occurred.

[2] Interviews explored the diary experience, the application and assessment processes at DWP and getting feedback on possible improvements including the three suggestions raised in the White Paper.

The impact of fluctuating conditions can be more comprehensively understood through asking detailed questions concerning the cycle of fluctuation detailed as a ‘framework’ below and described in this report. The cycle is relevant across different fluctuating conditions and individual contexts.

The current DWP disability application and assessment processes do not make it easy for people with fluctuating conditions to describe changing levels of disablement that they experience. This has caused differing degrees of difficulty, frustration, fear, and a sense of inequality for applicants with such conditions.

A framework for understanding fluctuating conditions

From the research we identified a framework (detailed in Section 4) for considering cycles of fluctuations that individuals may experience. These cycles can be more or less predictable or manageable, shorter or longer in duration, and of varying severity and net impact on an individual’s capability to undertake daily living activities.

The underlying condition

The cycle is founded on a wide range of underlying conditions (detailed in Section 4.2.1) with symptoms which impact an individual’s physical, cognitive and/or emotional capabilities. These symptoms vary individuals’ health and mental health outcomes over time. Many people have more than one co-occurring condition. 80% of survey participants had two or more conditions. Underlying condition/s vary in how predictable or manageable they are.

Trigger

A fluctuation in physical, cognitive and/or emotional capabilities often described as a ‘flare up’ may have an identifiable or unknown trigger. Some triggers such as weather are common across a wide range of underlying conditions. Other triggers correlate closely to specific access needs, such as exercise being most prevalent as a trigger for people with mobility or dexterity impairments. Triggers are detailed in Section 4.2.2, and Appendix D, Table 1.

Manage

People have different management approaches to minimise the regularity, severity, or impact of a flare up on their health and capabilities. Management approaches (detailed in Section 4.2.3) generally develop over time living with a condition and may include symptom prevention as well as dealing with symptoms during a flare up. Time since onset of the underlying condition can therefore impact knowledge and efficacy of self-management approaches, and of the impact of fluctuations on daily living.

Access to resources including financial, educational, and personal support can affect the ability to prevent or manage a flare up. Resources enable or limit access to medical, other professional or personal knowledge and support, and the ability to pay for medication or other helpful aids. Some people also have greater or lower degrees of flexibility in their lives to deploy management practices such as getting more rest/sleep or doing less.

Outcome

The outcome of a flare up can be a reduction in physical, cognitive, or emotional capability. In the diary study, participants described such outcomes, with negative physical outcomes being the most commonly mentioned, followed by negative cognitive outcomes, and then negative emotional outcomes. Besides impacting capability, these outcomes, detailed in Section 4.2.4, impact a person's sense of physical and mental health and well-being.

Impact

The impact on the individual's life, detailed in Section 4.2.5, includes their ability to undertake activities including the seven that we specifically reviewed for this research. These included: household, work, education/training/learning, social, leisure, financial, and travel. Some activities may be linked. For example, travel may be required to undertake work, education, or social activities. Daily living activities can demand a great deal of planning, support and understanding not only by the individual impacted by a fluctuating condition, but also from those around them such as others in the household.

Combined, these five elements can help someone describe their fluctuating condition in a way that can deepen an understanding of the challenges and has applicability to the DWP application and assessment process.

Experience of the DWP disability application process

The disability application process was largely viewed as being complex, daunting to start, and draining to complete for people with fluctuating conditions.

Applicants fear that they will be misunderstood if they include days when they are less impacted by their symptoms. Concerns about being misunderstood were associated with a lack of trust in the way DWP makes decisions.

Application questions give little opportunity to provide information on changes in conditions and the context of these changes. This includes describing triggers, predictability, and manageability of fluctuations, and the impact on capability and everyday activities.

Experience of the DWP disability assessment process

Many felt that there was a lack of flexibility and alignment to needs and experiences in the disability assessment process for claimants with fluctuating conditions.

- As with the application process, there were fears about being misunderstood in an assessment by those with fluctuating conditions.
- Fluctuating conditions made it difficult for some claimants to communicate, process information, and answer questions in an assessment.
- Questions asked in the assessment did not effectively enable claimants to convey changes in symptoms across time and the impact of these.

- Some research participants felt that assessors were unprepared, showed a lack of empathy, or asked unnecessary questions.

Potential future improvements

The research identified a range of ways that could make it easier for DWP benefits applicants to describe their conditions and fluctuating levels of disablement more easily, accurately and confidently.

During the depth interviews participants made suggestions for improvements to the current DWP application and assessment process that they felt would make the process more accessible, efficient, usable and build greater confidence and trust.

We identified four potential areas where DWP applications and assessments could be strengthened, informing both the process and how decisions are made.

1. **Improving the questions** asked of applicants within the application and assessment process. Questions could be aligned to the five-part framework to better understand the individual's
    - underlying condition/s
    - triggers
    - ability to prevent or manage flare ups
    - outcomes in terms of physical, cognitive, and emotional capability, and
    - impacts on everyday activities and compromises or implications of activities.
2. **Providing greater flexibility** in the application and assessment process. This includes
    - more flexibility in the time available and formats for applicants to provide evidence of the impact of their conditions. Allow applicants to change dates for assessment when experiencing a flare up.
    - reducing the length and complexity of the application as much as possible.
3. **Upskilling health and disability assessors** at induction and through ongoing training on the varying access needs and implications of claimants with fluctuating conditions. This should include knowledge about the predictability, manageability, and varying fluctuation cycles experienced by many applicants.
4. **Providing additional support and guidance** to help claimants describe the impact of fluctuating conditions through the process. This could be in-person support to help complete the application, from someone who understands their fluctuating condition. Preferences varied as to whether this should be support provided by DWP or from another organisation.

These changes could better inform the decisions to take fluctuating conditions into account, helping to build trust and confidence in the DWP disability benefit process.

Testing three specific ideas

Three ideas that had been initially described in the DWP "Transforming Support: The Health and Disability White Paper", March 2023[3] (The White Paper) were specifically tested with interview participants.

1. Direct supply of medical evidence by a GP or the NHS
2. Creation of a health impact record
3. Access to specific assessors trained to better match an applicant's main health condition.

Each of these approaches tested positively conceptually, with participants thinking that they could make it easier to evidence their conditions and impacts of associated fluctuating capabilities on their lives to DWP. However, many participants had concerns about the implementation of the approaches in practice, with respect to ensuring their positive impact on assessment fairness and efficiency. These included the administration of the schemes and how information would be interpreted by DWP. These and additional concerns are detailed in Section 5.4.

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[3] Transforming Support: The Health and Disability White Paper, 16 March 2023, ISBN 978-1-5286-3687-2 https://www.gov.uk/government/publications/transforming-support-the-health-and-disability-white-paper

1 Introduction

1.1 Background

DWP’s Health Transformation Programme (HTP) is modernising health and disability benefit services in the UK. It is doing this through implementing improvements to the Health Assessment Service (HAS) and the Personal Independence Payment (PIP) end-to-end journey.

These changes aim to:

- Create a more efficient service and an improved claimant experience.
- Create a more effective and efficient service for the taxpayer, reducing reliance on paper and clerical activity and integrating service delivery and IT systems.
- Reduce the journey times for assessments.
- Develop greater capability to innovate and deliver change.
- Improve trust in the services and decisions.

DWP has commissioned a range of qualitative research with people that have disabilities and health conditions, with DWP staff working within the HTP and with health disability assessors to inform the HTP. This current research project is part of this programme of research.

1.2 Objectives of the research

The overall aim of the research was to help understand how application and assessment processes can best account for conditions that fluctuate or change over time. To do this, DWP wanted to develop an evidence base that improved their understanding of fluctuating conditions, including their range and impact, to support improvements in application and assessment processes.

Fluctuating conditions are complex, and it is recognised that the current disability benefit assessments do not always fully consider the range and impact of these conditions.

The research set out to identify:

1. The experience of fluctuating conditions and how people manage and accommodate fluctuating conditions including,
    - Frequency and duration of changes, and triggers of change.
    - Functional and emotional experiences of fluctuations and impact on daily life.
    - How fluctuations are avoided or managed and supported when they occur.
    - Barriers, challenges, and problems experienced during fluctuations.

2. The best way to capture the impact of conditions which fluctuate, experiences of and potential improvements in the DWP process of application and assessment.

1.3 About this study

This report provides findings from a mixed-method (quantitative and qualitative) research study with people with disabilities and fluctuating health conditions conducted across the UK between mid-January and late April 2023. Three sequential research methodologies: an online survey, a diary study, and depth interviews, were selected for this project. They were chosen to provide an appropriate, effective combined approach for investigating and better understanding fluctuating conditions. Further detail is provided in Section 2.

Participants in this study had a broad range of fluctuating health conditions and disabilities (see Section 1.4. and Section 2.5 for more information) that varied in underlying condition/s, severity, timing of initial onset, and how it disables them. Many of the participants had multiple co-occurring conditions.

The next section of this report (Section 2) gives summary information about the research methodology, while a full methodology statement is provided in Appendix A.

1.4 Defining ‘fluctuating conditions’

Many health conditions vary, some significantly. Fluctuating conditions are not specific ‘conditions’ in themselves. Fluctuating, in this context, relates to a wide range of possible underlying conditions, where symptoms vary over time.[4]

Variation may be temporary, or it can be a part of a more permanent pattern of deterioration or improvement depending on the situation, trigger and type of condition to which it relates. A disabling underlying condition that fluctuates presents functional changes to physical, emotional, or cognitive ability that vary in severity and frequency.

There is no definitive list of fluctuating conditions. Common examples of physical conditions include multiple sclerosis, asthma, or diabetes. This research was designed to also include fluctuating mental health conditions, such as anxiety disorders or depression, and cognitive conditions, such as ADHD.

This study included people with fluctuating conditions that met two criteria:

- Severity of symptoms or conditions observably changed over time.
- These changes caused at least one significant impact in everyday activities.

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[4] For an more detailed definition of “Fluctuating Conditions” please see The Business Disability Forum Factsheet: Fluctuating and Recurring Conditions, Feb 2022 https://businessdisabilityforum.org.uk/knowledge-hub/resources/factsheet-fluctuating-and-recurring-conditions/

1.5 A note on language

It is important to consider appropriate language, when talking to or about people with different lived experiences of disability. This can be difficult as there is not an agreed “correct way” to talk about disability and long-term functional differences.

We know that people make different language choices based on their region or community, and even people in the same area with similar needs don’t always agree about how to use language.

In the UK the disability community tends to prefer identity-first language, since it is an important part of many people’s identity. Disabled people in the UK would be more likely to write or say, “I’m a disabled customer who regularly uses your service” or “This would support disabled people’s needs.” We have adopted this approach in our reporting. We also try to reflect specific language preferences of participants themselves in discussing their personal disabilities and/or health conditions.

2 Methodology and sample

2.1 Overview

Three research methodologies were selected for this project. They were chosen to provide an appropriate, effective combined approach for investigating and better understanding fluctuating conditions.

The three research phases were:

- Stage One: Online survey.
- Stage Two: Diary study.
- Stage Three: In-depth interviews (online).

All stages were conducted with people who had one or more fluctuating conditions as defined in Section 2.5.

The next section of this report gives more information about each stage and a full methodology statement is provided in Appendix A.

2.2 Stage One: Online survey

What was involved: The online survey was designed to capture a breadth of understanding about how a condition might fluctuate (frequency and duration of changes), what might trigger these changes, their impacts and how participants are supported.

Who was involved: Fieldwork ran from mid-January to mid-February 2023. A total of 297 participants completed the survey[5]. Each identified that they had a long-term condition or multiple conditions which changed or fluctuated over time.

The range of broad condition categories represented included:

- Long term conditions/mental health (n=176).
- Mobility/dexterity (n=166).
- Cognitive (n=77).
- Sensory conditions (n=76).

Many participants experience more than one co-occurring condition. The sample was drawn primarily from Open Inclusion’s diverse community of more than 750 individuals who sense, think, and move differently. It was further broadened by sharing the survey through disability charities and NGOs and by asking community members to share the survey with others they knew with fluctuating conditions.

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[5] Further information on the selection process can be found in section 2.7.

In terms of the spread across categories of disability and breadth of conditions, the survey achieved high enough base sizes for sub-analysis. However, the findings are not representative of all people with disabilities and conditions in the UK so should not be extrapolated to a wider population. Appendix B provides the breakdown of participants in the survey, including demographics and benefits status. Section 2.7 provides more detail on sample interpretation.

All participants were offered the option to do the survey in an alternative format such as by phone or using a Word document if they preferred.

2.3 Stage Two: Diary study

What was involved: The diary study was designed to capture a self-rated measure and qualitative understanding of physical and mental health changes that occurred across a 4-week period. It looked to further understand how these changes impacted the participant. It was made up of the following tasks:

- **Task 1 captured a baseline description** of physical and mental health and how symptoms were on day one of the study.
- **Task 2 asked participants to make an entry whenever they experienced changes.** It allowed for ongoing capture of insights over the four-week period when symptoms significantly varied. Participants could make as few or as many entries as needed. Each diary entry included a description of the change, a scoring of physical and mental health, and a description of related impacts.
- **Task 3 involved weekly roundups** where participants shared how their week had been and any possible impacts of flare ups and fluctuations going forward.
- **Task 4 asked participants to reflect on the diary study** as a whole and share anything additional about diarising that they wanted to draw the researchers' attention to.

Who was involved: Diary study participants were selected from the online survey respondents. They were targeted to include a spread of participants by age, gender, type of conditions, regularity/duration and reported impact of fluctuations or changes in condition. Appendix B provides the breakdown of participants in the diary study including demographics and benefits status.

A total of 46 participants completed the online diary study over 4 weeks (between 14 March and 13 April 2023).

Over the period the 46 participants provided 804 individual entries (online, Word or WhatsApp). 544 were related to Task 2, daily entries reflecting changes in symptoms.

2.4 Stage Three: Online in-depth interviews

What was involved: The third stage of research entailed in-depth interviews, designed to explore:

- Issues participants felt they could not discuss in the diary study (allowing individuals to self-describe more fully and accurately).
- Experiences of DWP application and assessment processes.
- Potential improvements to the application and assessment process and questions asked during the process.
- Feedback on three ideas from the DWP Policy Paper “Transforming Support: The Health and Disability White Paper”, March 2023[6] These included the Health Impact Record, an option for DWP to access information digitally direct from GPs or other health professionals to support a claim, and the option of access to specific assessors trained to better match an applicant’s main health condition.

Interviews were conducted by researchers from Open Inclusion and Basis Social between 11th April and 28th April 2023. Interviews lasted up to 60 minutes, depending on individual needs. They were carried out online via Microsoft Teams.

Who was involved: A total of 49 participants completed an in-depth interview. This included 46 participants from the diary study and 3 participants who were invited to the diary study but opted only to complete an in-depth interview.

2.5 Participant eligibility

Participants were eligible for the research if they were aged 18 or older and living in the UK and they observed that the severity of their symptoms or conditions changed over time. They needed to observe at least one significant impact in everyday activities due to these changes.

There is confusion about and varying perspectives on what a fluctuating condition is. We were careful to avoid the term ‘fluctuating condition’ in the recruitment process so that potential participants did not exclude themselves due to how they identified.

Instead, we provided a broader definition of what could constitute a fluctuating condition as we wished to define it for this research and allowed participants to self-select for the survey and the research stages that followed. The definition was:

- **Fluctuations could happen frequently or occasionally**. They might also return after going away for a period of time.
- **Fluctuations in a condition could be**:
    - Physical health changes – for instance pain, energy levels, changes in mobility or dexterity or a change in glucose or blood pressure.
    - Mental health changes – for instance depression, increased levels of anxiety, memory challenges.
    - Sensory changes – for instance sensory overwhelm or sensitivity to light or sound.

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[6] Transforming Support: The Health and Disability White Paper, 16 March 2023, ISBN 978-1-5286-3687-2 https://www.gov.uk/government/publications/transforming-support-the-health-and-disability-white-paper

- **Changes in symptoms could be a response to:**
    - How conditions are managed and a sign that something needs to change.
    - Triggers such as diet, exercise, weather, additional stress, or illness.
    - A feature of a condition or something that changes on a daily basis.

2.6 Analysis and interpretation

Quantitative analysis of the survey data involved reviewing the responses to open and closed questions overall and by condition category.

Qualitative analysis of the diary study, the interviews, and the open questions from the survey involved the development of a coding framework to analyse and synthesise insights. The coding framework was based on the research objectives and topic guide and was also inductively developed from the data.

Through detailed analysis and interpretation of qualitative and quantitative data, patterns of responses and relationships were identified, leading to well-supported conclusions.

This was supplemented by regular brainstorms between members of the field team in Open Inclusion and Basis Social to identify and sense-check themes and conclusions.

2.7 A note on interpretation

Quantitative research

297 people completed the online survey. Participation in this survey was ‘self-selecting’ amongst an established community used for research by Open Inclusion plus some additional outreach to boost numbers. Therefore, the findings are not representative of all people with disabilities and conditions in the UK.

Given limited nationally representative data and knowledge of the full extent of fluctuating conditions across the UK, the data is not weighted, and all results are based on unweighted findings.

Qualitative research

It is important to note that qualitative research is designed to be illustrative, detailed, and exploratory. It allows us to better understand the “why” behind the responses selected in the survey and, particularly in the interviews, it allows probing in response to information provided.

It offers insights into the perceptions, feelings, and behaviours of people rather than quantifiable conclusions from a statistically representative sample.

Verbatim quotes have been used throughout this report to help illustrate points made in the main narrative. These have been labelled according to a broad category of disability and/or health condition and by the participant gender and age. Some quotations have been modified slightly for readability.

We have also included several pen portraits, based on the anonymised experiences of participants, and selected to bring the findings to life. The names are pseudonyms and we have ensured that there is no detail in the descriptions or quotes that might be personally identifiable.

3. Understanding fluctuating conditions

3.1 Introduction

Symptoms for many long-term health conditions vary over time, some significantly. This means that symptoms can worsen and then improve for periods of time, or improve then worsen. This creates changing levels of personal disablement and ongoing uncertainty. We start this report with an exploration of fluctuating conditions from the participants' perspectives.

All participants in the research previously stated that they had at least one condition which fluctuated to the extent that it impacted their life in at least one area.

3.2 Diversity of fluctuating conditions

Participants had a wide diversity and variability of 'fluctuating conditions', across the following categories, (see Appendix A Table 1 for more detail).

- Sensory: D/deaf[7], hard of hearing, blindness, and low vision.
- Mobility/dexterity: participants using a wheelchair or who experience restricted ambulation (ability to walk without assistance). Those with dexterity challenges due to tremor, missing upper limb or hand, low grip strength or control.
- Cognitive: Specific learning difficulties (such as dyslexia, dyspraxia, or dyscalculia), other neurodivergent[8] conditions for example autism or attention deficit hyperactivity disorder (ADHD), "brain fog" and memory challenges.
- Other long-term health conditions: long-term conditions that do not fall specifically just in one of the three categories above but have a range of symptoms often relating to internal bodily system dysfunction such as diabetes, multiple sclerosis, heart conditions, epilepsy and inflammatory bowel disease.
- Mental health conditions including anxiety, depression, trauma-based conditions such as PTSD, phobias, bipolar disorder, or other mental health conditions.

This diversity means that fluctuating conditions cover a wide variety of symptoms, impacts and outcomes that were described by participants through the research. Even within any single condition or category, there is significant variation in people's experiences of fluctuations and their impacts on their lives. Individual experiences of

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[7] The D/deaf community in the UK includes people who identify as capital D Deaf as well as those who don't feel a need to capitalise the word. Those who denote the word with a capital D identify as part of a cultural and linguistic community in addition to it denoting an auditory state. The community that capitalises Deaf tends to use British Sign Language (BSL) as their first language.

[8] People who are neurodivergent have neurological patterns of thinking and learning that significantly diverge from the majority across an appropriate reference community.

fluctuating conditions are shaped by the frequency, duration and extent of capability change and what happens in the context of their lives when this occurs.

What was consistent across the experiences described was that the impacts on day-to-day life were variable and subject to uncertainty.

Co-occurring fluctuating conditions

We had a high level of co-occurrence of conditions within our sample. A majority (80%) of participants in our online survey experienced conditions across two or more broader categories e.g. mobility/dexterity and cognitive.

The level of complexity introduced by co-occurring conditions is important. It makes singling out the impact of a single condition more difficult. It can add to the number, combination, and types of triggers, the range and severity of worsening symptoms, degrees of manageability, and impacts.

Participants in the research reported:

- How changing symptoms in one condition could trigger symptoms in another.
- Avoiding triggers for one condition could mean creating triggers for another.
- Engagement in management or self-care approaches for one condition could change symptoms for another condition (worse or better).

For example, one participant in the diary study noted how her use of hearing aids could worsen symptoms associated with her MS.

> “I wear hearing aids, but part of my MS is that parts of my body are extremely sensitive and painful. Last night I kept waking up with earache and by morning it had turned into a headache too. I have not been able to wear my hearing aids today and I’m not sure I will again tomorrow. What a pain! I’m worried about these conflicting problems. Pain levels have to come first over hearing."
>
> (Diary, female, 55-64, sensory and long-term health and mental health conditions)

Worsening physical health symptoms were also associated with negative sleep and cognitive function.

> "I am still dealing with ongoing excessive trapped wind, bloating and a distended stomach. The pain is very bad. It has affected other areas as I’m not sleeping very well because of it, so I am exhausted and feel very weak and my brain feels foggy...there has been no trigger as I have only been eating known safe foods."
>
> (Diary, non-binary, 25-34, long-term health and mental health conditions)

3.3 Living with a fluctuating condition

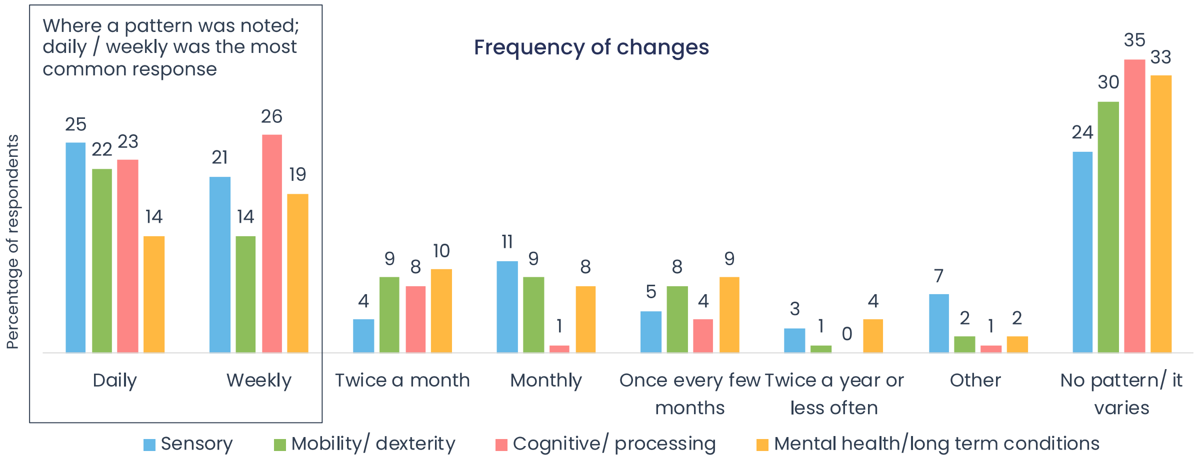
Fluctuating conditions are difficult to live with relative to more stable underlying conditions of equivalent severity due to the uncertainty and complexity of managing symptom changes.

Changing symptoms means being able to engage in activities one day and not another, or having to ask for support one day and not another. It means not knowing what may be possible tomorrow or next week. The disruption caused by changing symptoms, and the flexibility needed for support and adjustments, is often hard to cope with or describe.

3.3.1 Variability in frequency and duration of changes

Frequency: how often

Figure 3.1 shows the frequency of changes in symptoms for participants in the survey.



Q: How often do you typically experience significant changes to your condition(s)? [9]

Base: All participants noting changes in reference to condition type: Sensory (76), mobility/ dexterity (166), cognitive (71), long-term conditions and mental health conditions (176) N.B. Those who answered "Don't know" are not shown

A high proportion of participants noted no consistent pattern to the frequency of their symptom changes (24% - 35% by condition type).

Of those who did note perceptible patterns to their symptom changes, daily or weekly frequency was the most common across all condition categories (33% - 49% by condition type).

There were also some differences in patterns between specific condition categories. For example, for those experiencing sensory conditions, just under a quarter (24%) noted no pattern, relative to more than a third (35%) for those with cognitive/processing conditions.

> "It varies so much. In my life the fluctuations feel longer and based around life events rather than my condition, with milder symptoms changing day by day if I stare at a screen too much etc."

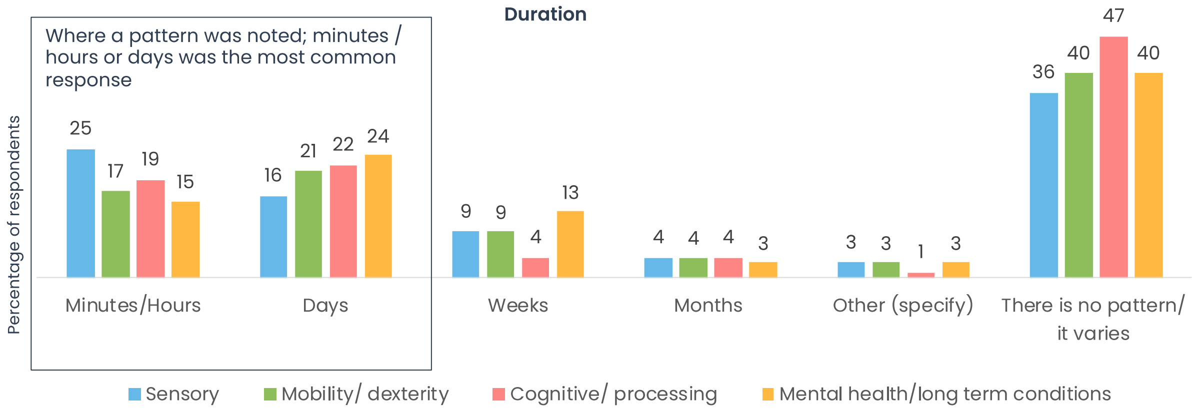
---

[9] This chart uses colour to depict the different community groups. It also uses order or position. Should you find colour hard to perceive, the order of each set of bars is the same as the order of the key (1st sensory, 2nd mobility/dexterity, 3rd cognitive and 4th mental health and long-term health conditions).

(In-depth Interview, female 45-54, sight loss)

Further details on frequency of fluctuations including additional quotes can be found in Appendix C.

Figure 3.2 shows the duration of changes in symptoms (including recovery) for participants in the survey.



Q: How long do significant changes to your condition(s) usually last for? Please include the time that symptoms are more severe and the recovery time you may need.

Base: All participants noting changes in reference to condition type: Sensory (76), mobility/ dexterity (166), cognitive (71), long-term conditions and mental health conditions (176) N.B. Those who answered “Don’t know” are not shown

Many participants have very little sense of how long changes in symptoms caused by a flare up will persist. Depending on the condition type, between a third and nearly half of all participants noted no observable pattern to how long changes lasted (36% to 47%).

Where people did notice a discernible pattern of duration, the changes were more likely to last for hours or days rather than weeks or months.

Further information on specific category patterns is detailed in Appendix C.

Variations in patterns of fluctuations, including duration and frequency, are important for consideration in the design of the DWP benefits application and assessment processes. The application and assessment processes would best enable the capture of information on an applicant’s capability by providing them with the opportunity and flexibility to outline the extent and context of symptom fluctuations, so that the impacts can be understood over the most relevant time span for them. This would recognise the relevance of their specific frequency or duration of symptom changes.

3.3.2 ‘Good’, ‘usual’ and ‘poor’ periods

At the end of each week, diary participants shared a reflection of their week. They defined their experiences into one of four broad types: good, usual, mixed, and bad.

While each is explored in more depth below it is worth highlighting that there can be no firm definition of each, or conclusions drawn about the impact of different types (or combinations) of condition. These are subjective, experiential, and relative, with participant's reflections moderated by a range of other factors as we will go on to discuss. Some participants reported a good week while reporting a lot of symptoms. This highlights how relative this is: it was a good week *for them*.

Experience of a 'good' week

Good weeks were weeks when the participants felt they were managing their condition/s reasonably well, were able to complete as many activities as they hoped (or more than they hoped) and felt good about themselves.

They often noted one or more of the following during the week. They,

- Managed to get through work or social commitments.
- Received positive news about a treatment.
- Experienced no new symptoms.

> "This week has been a good week. At the start I was struggling with my balance and fatigue. Fortunately, it is now better although my balance is still not good."
>
> (Diary, female, 75-84, long-term health condition)

Experience of 'usual' weeks

Usual weeks were weeks when participants may have had challenges and successes in undertaking activities or how they feel across the period, but they accepted these as being in line with their expectations of what are normal changes.

They often noted one or more of the following during the week. They,

- Talked about their flare ups in a very pragmatic way.
- Noted that changes in functional capability were similar to those usually experienced and that their frustration with changes as also not being unusual.

> "An average week pain and conditions wise despite doing things that I don't usually do. A new pain where my left thumb joins my left hand is something I can do without. Diarrhoea and constipation is about on schedule. Tiredness was up and down as it always is."
>
> (Diary, male, 45-55, cognitive, long-term and mental health conditions)

Experience of 'mixed' weeks

Mixed weeks (some good days and some bad days) were described by participants with more significant variation in successes and challenges across the period.

They often noted one or more of the following during the week. They,

- Had the opportunity to implement some effective management techniques such as rest / time off work on the weekend or on holidays or going to therapy.
- Experienced a flare up or change such as a trigger being encountered during the week.

> “I have had a mixed week of positive and negative changes to my condition. I had a flare up of my symptoms for 3 days including a lot of pain and stiffness. When the flare up receded I was able to go to physiotherapy and had a very positive session which improved my mood significantly.”

(Diary, female, 55-64, dexterity)

Experience of ‘bad’ weeks

Bad weeks felt uncommonly challenging relative to their personal expectations (i.e., what they were used to).

On a bad week participants often noted one or more of the following. They,

- Experienced severity of pain or symptoms that was worse than usual
- Experienced new symptoms.

> “It's been a rollercoaster. My pain has at times been off the charts. Which had impacted on my mental health and wellbeing. These illnesses change who you are forever and sometimes you mourn the loss of your former self. Knowing there is no definitive cure does not help. But yet, somehow, we go on.”

(Diary, female, 65-74, dexterity, long-term and mental health conditions)

3.3.3 Fluctuating conditions affect physical and mental health

The diary study charted how participants felt both physically and mentally across a four-week period. For each diary entry relating to a change in symptoms, participants were asked to score themselves between 1 and 5, (with 1 being not good at all and 5 being very good) separately in terms of their physical and mental health.

Overall, findings show that fluctuating conditions and capability impacts both mental and physical health, and that these effects vary. Physical health and mental health can move in the same or in opposing directions.

As these measures were self-assessed we note that they will be highly influenced by the participant’s sense of what is a ‘normal’ level of physical health or mental health to them.

Physical health

Physical health was typically understood as relating to pain, mobility and energy levels.

Overall, participants were more likely to report poor physical health than good physical health during the 4-week study period.[10]

Variation in health went both up and down for most participants across the period,

> "After experiencing a bad flare up in my arthritis symptoms including joint swelling and pain 3 days ago, those symptoms have now eased. I am feeling a lot less pain and stiffness and I have slept well. My husband didn't need to help me get dressed and I managed to shower and dry myself without help today."
>
> (Diary, female, 55-64, long-term health conditions)

Just a few noted variations in physical health across the full spectrum, from 1 to 5. The most common range of variation for participants to note across the diary study period was 2-3 points. There were a wide range of reasons provided for variations which were individual and condition based. It is not possible to provide a clear sense of the common driving factors behind changes to perceptions of physical health due to these variations.

We know from interviews that some people dropped off in their self-reporting via the diary when symptoms increased in severity. Managing their fluctuations was taking all their energy and focus. This may have reduced the number of very low ratings being recorded and included in the dataset.

When describing changes, participants often reported more than one symptom being experienced simultaneously in relation to physical health.

> "I have spent most of the last week in a lot of pain and severe brain fog, a side effect of my medication and also my flare up of my condition. I have been unable to carry out any of my usual tasks and have slept a lot. I have been unable to eat, due to complete exhaustion, so have mainly snacked."
>
> (Diary, female, 45-55, long-term health and mental health conditions

Mental health

In the diary entries mental health comments typically related to depression, anxiety and symptoms related to mental health illnesses (e.g. schizophrenia).

For this particular cohort of participants, mental health ratings were more positive than physical health at the start of the study.

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[10] These scores may have been impacted across the month by more pervasive seasonal or other impacts such as holidays or weather, but this study was too limited in scope to accurately reflect any such broader patterns.

This initial rating fell for many during the study. Nearly half of the participants noted a mental health score at the lower end of the scale (1 to 2 rating) at some point during the 4-week period.

Some mental health declines noted were quite severe.

> “I have been extremely tired and fatigued recently and almost like all energy has been sucked out of me with a hoover. It has affected me mentally and socially as I have been unable to leave the house. I have been very irritated and very snappy to the people I live with. My concentration has been affected also and motivation for having a shower, getting dressed and housework.
>
> (Diary, non-binary, 25-34, long-term health conditions)

Changes in mental health could take time to improve after whatever had triggered a fluctuation in their condition was no longer a trigger.

> “I felt really exhausted, overwhelmed, and disoriented. I think because this felt too much. I wasn’t able to stay present and I dissociated. When this happens, I feel out of my body and take a few days to feel ‘normal’ again.”
>
> (Diary, female, 18-24, long-term health conditions)

3.3.4 Fluctuations often have a negative impact on cognitive and physical capability

Fluctuations had a wide range of specific impacts which we describe in detail in Section 4.2.5. The more general limitations on people’s ability to participate in tasks and activities of daily life included:

- Having limited ability to do anything other than rest.
- Limited cognitive bandwidth including processing information and communication.
- Needing to reduce social commitments to prioritise rest and manage fluctuation.
- Less mental and physical energy for doing activities of daily living (like preparing food, caring, housework) or physical activity.
- Needing to adjust activities due to pain or symptom flare ups.

Outlined below are some specific examples of these impacts shared by participants in the research.

When symptoms were flaring many described that they had limited ability to do anything other than rest.

> "Other people might say, ‘Well, it's the weekend. I'm gonna go out.’ Whereas I'm like, OK, I need to use my weekend to recover so that I can work again on Monday, because otherwise I can't work."
>
> (Interview, female, 25-34, mobility and long-term health condition)

Many participants noted that they had reduced bandwidth for problem solving.

> “When I cross the road, I mistakenly see the red icon of a person on the crossing as meaning it's safe because drivers will see a red light. When we get mixed up with simple stuff it isn't easy.”
>
> (Diary, male, 55-64, cognitive and multiple long-term health conditions)

Adjusting plans and activities to manage changing energy and capability levels frustrated many participants.

> “Yesterday in the night I remember half waking up when turning over and realising that I had a migraine. I was too tired to wake up and take any medication. By the time I woke up in the morning it was really bad. I went back to sleep. I hate missing whole days due to illness.”
>
> (Diary, female, 55-64, long-term health conditions)

3.3.5 Describing fluctuating conditions can be difficult

Participants said that it could be difficult to describe their conditions and their impacts on daily life in a meaningful way. This could make it hard for people around them to understand their challenges. Describing challenges to others was even more complex for the many participants who had co-occurring conditions.

This is particularly relevant to DWP as it also affected how able people felt in describing the impact of their condition within benefit applications and the assessment process.

A number of participants worried about being believed by medical and non-health professionals as symptoms common to fluctuating conditions such as pain and low energy levels are often not visible to others.

> “Explaining symptoms is often difficult as they seem so generic and I worry it sounds like I am just making excuses, particularly in professional settings. With such a rare condition I find I often have to constantly explain and justify, and that effort in itself is exhausting.”
>
> (Survey, female, 25-34, sensory and long-term conditions)

Participants were concerned when professionals responded more generally to typical symptoms of a condition and didn't respond specifically to the individual's reported experience.

> “I have sometimes found that a professional 'hears' what I'm saying but doesn't 'listen' and understand me. They can sometimes assume they're familiar with the problems I'm describing and dispense advice about a different problem. I'm more hesitant to discuss new problems with them in case it means they've misunderstood my circumstances and form incorrect opinions.”
>
> (Survey, male, 35 to 44, cognitive condition)

Sometimes participants had experienced both issues combined.

> "The main one is the fear of disbelief, which is an often-founded fear. I live with debilitating symptoms and rarely complain and ask for help. When I do, I get generic advice and no real help…"
>
> (Survey, female, 35 to 44, cognitive and long-term conditions)

More broadly lack of disability-inclusive awareness, specifically as it relates to fluctuating conditions can make any communication difficult. This in turn impacts the extent to which participants could manage their condition, and therefore moderate the impact on their day-to-day living.

> "Workplace stigma and lack of understanding/training makes it hard to discuss my disabilities and their fluctuating nature."
>
> (Survey, male, 25 to 34, cognitive condition)

From survey participants we gathered a breadth of insights about issues they had experienced when trying to explain symptoms or conditions to professionals (health and non-health). The top two most common problems mentioned were:

1. **Problems explaining symptoms and impacts**: participants struggled to clearly articulate or explain symptoms due to a number of reasons, including:
    - Personal confusion about new or worse symptoms and not knowing the cause.
    - Symptoms of the condition itself making the conversation difficult: participants mentioned confusion, memory challenges or brain fog.
    - Feeling stressed and frustrated at the lack of understanding shown.
    - Not liking to open up or talk about disabilities and conditions. A diary study quote also described this more cultural challenge.

    > "We disabled don't really like drawing attention to ourselves, it seems selfish and impolite. It isn't others' fault they can't and don't understand our limitations so why get cross with them by forcing them to face something they will never understand until they are disabled. They've got their own lives to lead, so we just muddle on."
    >
    > (Diary, male, 55-64, cognitive and long-term health conditions)

2. **Lack of knowledge or understanding** of the specific condition/s by the professional. Detailed as follows in Section 3.3.6.

3.3.6 Getting support from health and non-health professionals

The research highlighted that not all engagements with health and non-health professionals had been positive.

We have already outlined some of these issues just above in terms of describing conditions and being actively listened to and believed (see Section 3.3.5).

Issues with understanding the impact of changing conditions and knowledge of conditions were also common challenges as highlighted in the survey. This was observed across both health and non-health professionals (Appendix D Figure 2).

Survey participants reported issues with:

- Understanding how changes affect me or my life (62% reported issues in relation to health professionals and 55% for non-health professionals).
- Knowledge of my symptoms and conditions (56% reported issues in relation to health professionals and 49% for non-health professionals).

Providing sufficient time and communication clarity for patient/professional interactions were also issues for at least a fifth of survey participants:

- Being given the time it takes to discuss the issues (36% had an issue with this in relation to health professionals and 31% for non-health professionals).
- Problems understanding the questions being asked (22% had an issue with this in relation to health professionals and 21% for non-health professionals).

Being given sufficient time to communicate the issues without pressure and overcoming an overarching fear of not being believed about how a condition is impacting them are challenges for many. Accounting for these are important considerations for DWP benefit assessments in particular.

> “Under pressure I cannot recall words to complete sentences needed to explain myself. I feel like a fraud because I don’t look like someone with difficulties.”
>
> (Survey, female, 45 to 54, Cognitive and mental health conditions)

> “As I have a stammer they sometimes cannot understand me, and I try to use words I can say which sometimes means they don’t understand what I am trying to say. They talk over me and try to guess what I am saying.”
>
> (Survey, female, 35 to 44, Mobility/dexterity and cognitive)

Understanding and clarifying what is asked and meant in complex communication about fluctuating conditions (e.g. in communications with medical professionals, including within an assessment process) can be harder because of the condition/s themselves.

> “I never put questions down to ask the Consultant, or GP and I forget to write the symptoms I am feeling. I never challenge or question the drugs the GP gives me... It is only when I have left I have forgotten to ask about side effects etc...”
>
> (Survey, female, 45 to 54, Cognitive and long-term conditions)

3.4 Key takeaways for DWP

1. Fluctuations can vary between people, and for an individual, across time in terms of frequency, duration and what is a normal versus unusual range of severity.
2. Mental health and physical health can fluctuate independently of each other, in differing directions or one being more stable while the other varies.
3. When experiencing a flare up, physical and emotional energy can be significantly limited, reducing the ability to solve problems, communicate or do activities that may be required for applications or assessments.
4. Describing fluctuating conditions can be hard for many, especially when the condition itself makes engaging in complex communication more difficult.
5. People often don't feel understood or believed by health and non-health professionals, especially when the condition is not well known or the symptoms are more generic (such as fatigue and pain).
6. Time pressure can make describing a complex condition more stressful and difficult to do so clearly.

4. A framework to describe fluctuation cycles and impacts

4.1 Introduction

A key objective of the research was to explore the options for DWP to capture and better understand the impacts of conditions which fluctuate.

After a detailed analysis of the data, no condition, symptomology, or severity-based typologies emerged. Instead, a highly individualised pattern of conditions, triggers, management approaches, fluctuation outcomes and impacts became evident.

These are the consistent underlying foundations of a cycle that emerged as a useful way to ask about, and better understand, how impacts emerge for people with fluctuating conditions.

We believe that this framework could help DWP more effectively engage with applicants to gain a deeper understanding of their fluctuating condition/s and the varying degrees of disablement experienced across time.

It outlines a consistent set of considerations to be explored so that individuals can more fully, consistently, and confidently represent themselves when talking about a condition that fluctuates.

The framework recognises the huge complexity across individuals, in terms of how they may describe their conditions and the interconnected elements that positively or negatively influence how their fluctuating conditions impact their daily lives at any moment in time, and over time.

It is purposely not condition centred. Whilst of obvious importance, the underlying condition itself needs to be explored in a much wider context of its implications for an individual. This wider context involves gaining an understanding of the underlying condition in terms of its severity, manageability, and predictability, known or unknown triggers, how changes are managed, outcomes of fluctuations, and their impacts on ability to undertake daily living activities.

4.2 Overview of the fluctuation cycle

Below we outline each of the five elements in the cyclical fluctuating capability and impact framework. This chapter then goes on to discuss each element in more detail drawing from analysis of the survey responses, diaries, and interviews.

- **Element 1: The underlying conditions (including current predictability and manageability).** Understanding underlying conditions goes beyond knowing the name of any diagnosed condition/s. It includes how long since onset and diagnosis, how predictable or manageable flare ups or changes are for the individual and how severely they impact their capabilities and activities. It is the founding element that influences each of the other elements.
- **Element 2: Triggers**. Triggers can bring on, worsen, or change a condition. Triggers can be environmental (allergens, weather), related to other physical or mental health symptoms (contracting a virus, or periods of high stress or anxiety) or times when a change is simply a feature of a condition that needs to be accommodated. Triggers may be known or unknown, and known triggers may be predictable to a greater or lesser degree.
- **Element 3: Management of condition/s and symptoms**: Management of fluctuating conditions explores any actions taken to avoid or minimise negative outcomes including reduced capabilities, physical health, or mental health. Management techniques described by participants in this research include self-care, such as moderating activities and getting rest, use of medication, or therapy. Available management techniques incorporate the differing resources, flexibility, and support systems that individuals have. For example, having or not having adjustments in place at work or flexible home responsibilities due to household support. Management of fluctuations therefore depends on the range of possibilities given the nature of underlying condition/s as well as personal and contextual factors.
- **Element 4: Outcomes of changing symptoms:** Outcomes includes the level, regularity, and duration of the variance in physical, cognitive, and emotional ability as a result of an episode or flare up. Outcomes can be different for individuals with the same type of condition/s. Even for the same individual, they can vary from one fluctuation in symptoms to another, for instance time of year and the weather can impact how bad outcomes can be. Besides impacting specific abilities, flare ups can impact the individual’s sense of well-being, physical health, and mental health.
- **Element 5: Impacts of changing abilities:** The final element in the cycle looks to understand the impact of a fluctuation on daily activities able to be undertaken and any secondary implications. For example, a reduction in physical ability could impact any one or more of the following areas: activities in the home and self-care, social life and leisure activities, work and education or training, personal travel, or financial activities. For this research we have focussed on these seven areas of daily activities. These activities are outlined below in section 4.2.5.

4.2.1 Underlying condition/s (including the current degree of predictability and manageability)

To complement information about underlying fluctuating condition/s known by an individual, other useful contextual details to explore about underlying conditions are:

- **Time since onset** of the condition - how recently symptoms or changing capability started.
- **Recency of the diagnosis**, if there is one - when did medical professionals identify a cause of symptoms or impaired capability.
- **How severe** the symptoms or effects are – how disabling the condition/s are at their best and worst.
- **How variable** are the implications for an individual's life including regularity and duration of episodes or flare ups.
- **How stable** the condition/s are – over time are they stable, recovering or progressively degenerative.
- **Are there co-occurring conditions**, fluctuating or stable and how do co-occurring conditions (if there are any) influence each other.

These additional layers of information can influence the extent to which the individual has had the opportunity to understand their condition, why and how it fluctuates, and to make adaptions to their life to manage these fluctuations. These could include accessing personal support in the home, changes to the work they do or how they do it, adoption of suitable home adaptations or personal assistive technologies.

Please note that the concepts of severity and variability are inputs into changing capability and the impacts on daily activities. These are discussed further in Sections 4.2.4 and 4.2.5.

Being able to describe a fluctuating condition to others can be difficult

Irrespective of a person's experience of their condition/s, participants noted that it can still be very difficult for them to describe the impacts of them to others. One major reason is that 'normal' can be hard to judge when your normal is different to others and not stable.

> "Yesterday I went to a physiotherapy appointment about my new knee. It is not always easy to evaluate your own condition compared to other fitter individuals. For instance, I was asked if I could do my 'normal' daily activities of washing, dressing, working and household chores. Even before my recent operation these activities are nowhere near what a 'normal' person can do. My life is full of small adaptations that help me to just about manage daily activities, so assessing my progress against any sort of 'normal' criteria is difficult when my version of 'normal' varies wildly each day."
>
> (Diary, female, 45-64, dexterity)

Predictability and manageability

There are two other useful factors that can vary across conditions, individuals with the same condition, and the progression of a condition for an individual. These can be particularly important in understanding the complexity of fluctuations and their impact on an individual's abilities. These factors are,

1. **Predictability** – How consistently or regularly flare ups occur. If they are highly regular (e.g. every few days) that is more predictable than changes which happen much more rarely. Equally changes may be very predictable as the triggers are well known, but not regular, such as seasonal challenges.

   Highly unpredictable flare ups can be very difficult to manage as they are unexpected whereas greater predictability can make them easier to plan around. Despite this, predictability alone cannot be used as a marker of personal challenge, as even very predictable flare ups can be difficult to manage when they are severe in their impact and the impact is unable to be significantly moderated or avoided.

   > "Arthritis flares are unpredictable. With time I have become better at managing flares early on. If I have complete rest it can reduce the length of a flare from weeks or months to 4-10 days."
   >
   > (Survey, female, 45-54, long term condition

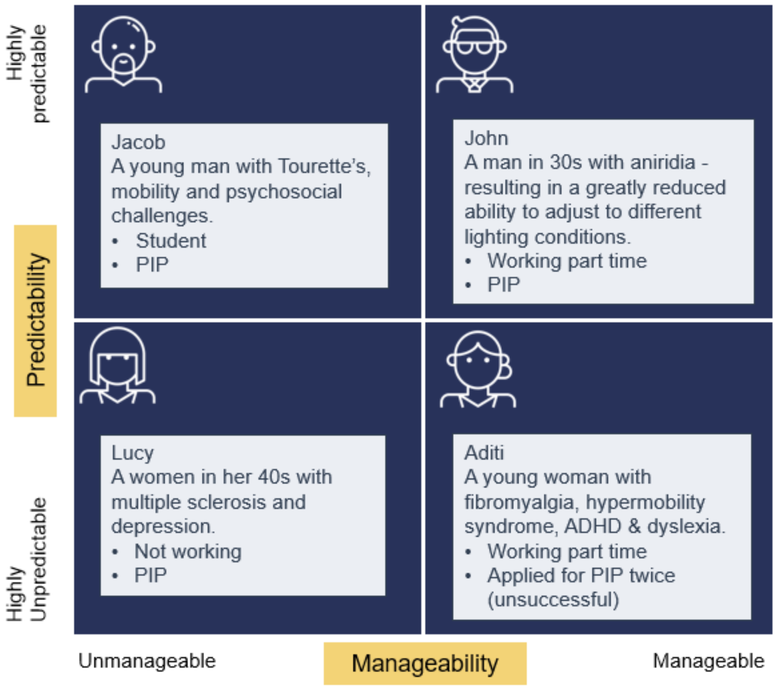
2. **Manageability** – Underlying condition/s may be more or less manageable. What options or approaches are available for the underlying condition/s that can help to avoid or minimise the negative fluctuations and the impacts of them on their lives.

   More manageable condition/s can have their negative impacts and flare ups avoided or reduced by using professional or personal support, medication, or self-management approaches effectively. However, some conditions are better understood by the medical profession than others and have had more time for drugs, treatments, and personal management approaches to be found and well tested.

   > "On Friday, I have a meeting with the medical nurse at the doctor's surgery. Discussed changes and how I might be able to reduce fluctuations with more medication."
   >
   > (Diary, male, 55 to 64, long-term conditions

Learning, trialling, and practising good personal management of fluctuating conditions can be complex and take time to work out. We will discuss the adoption of personal management approaches further in Section 4.2.3.

The extent to which conditions were predictable and manageable is central to understanding the impact of fluctuations. To illustrate this, we have included pen portraits of four research participants who each experience different underlying fluctuating conditions and diverse experiences of cycles of triggers, management, outcomes and impacts. The names used are pseudonyms. The degree to which conditions were predictable and manageable for each of these pen portraits was defined by the researchers based on their diary responses and interviews.



Jacob
A young man with Tourette's, mobility and psychosocial challenges.
- Student
- PIP

John
A man in 30s with aniridia - resulting in a greatly reduced ability to adjust to different lighting conditions.
- Working part time
- PIP

Lucy
A women in her 40s with multiple sclerosis and depression.
- Not working
- PIP

Aditi
A young woman with fibromyalgia, hypermobility syndrome, ADHD & dyslexia.
- Working part time
- Applied for PIP twice (unsuccessful)

All names are pseudonyms

Pen portrait: Meet John

Experience of fluctuating conditions

John is a man in his 30s with aniridia, a lack of irises in both eyes, resulting in a greatly reduced ability to adjust to different lighting conditions.

He experiences fluctuations with eye tiredness, which is almost always dependent on the amount of work he does and his exposure to bright light.

John has a predictable and manageable condition. He understands the triggers of fluctuations and is experienced with management strategies.

Known triggers include bright light and eye strain.

Experience of fluctuations

"My eyes are tired. I'm making silly little typos or just not really able to focus on work for very long. My eyes kind of move a bit more than usual, so I'm not really focused. And that's simply because I've had an intense day at work, lots of reading to do"

"Even taking breaks during the day fairly regularly, it still adds up altogether at the end. I just had to take it easy this evening and not do anything too intensive in terms of reading and focusing on things."

Considerations to better support John could include*

- Give the opportunity to provide information on fluctuating conditions, their frequency and impact.
- Provide guidance on how to best respond to the PIP form.
- Design documentation that minimises strain for those with low vision by having efficient and accessible formats
- Offer flexibility in the application process to ensure John has the time he needs, in case of fluctuations, to complete the form.

*Considerations are researcher generated based on participant feedback and overall findings.

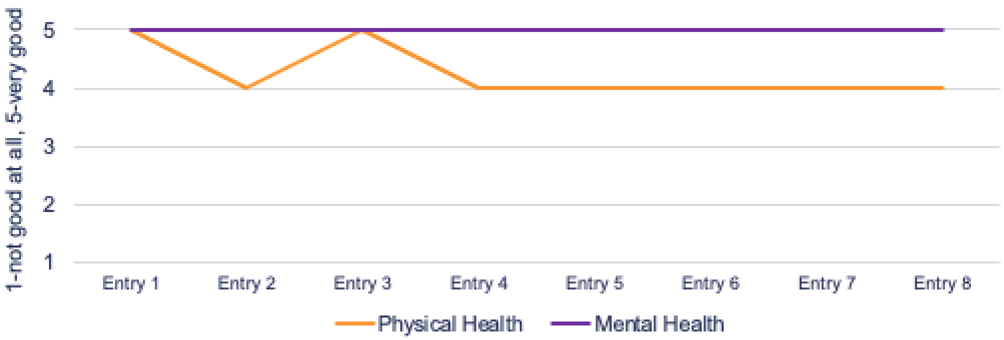
Impact of fluctuations

"Mentally, I'm feeling fine. Physically, I'm feeling fine. However, there is a problem going out because it's too bright lately. It's just bright and this can really affect me."

"Long intense days are causing more eye tiredness and this makes it difficult to engage in reading-based leisure activities or going out if it's bright."

John's mental health was continuously reported as 'very good". His reported physical health was also good, and it was not significantly affected by changes in his condition.

Diary study – physical and mental health rating
(1-not good at all, 5-very good)



Pen portrait: Meet Aditi

Experience of fluctuating conditions

Aditi is a young woman with fibromyalgia, hypermobility, ADHD and dyslexia.

She often struggles to get through her day. She experiences physical pain but also memory and focus challenges. Her basic daily activities such as eating and self care are sometimes affected by fatigue and a mental heath condition.

Aditi has an unpredictable but manageable condition. She finds daily functioning extremely hard. Rest and trying to avoid triggers helps.

She has a very wide range of triggers. Some are known, many are not.

Experience of fluctuations

"I can get very overwhelmed if there's too much noise or if there's too much going on, I just feel a bit like I just freeze because I just can't function like that "

"My mind feels very splintered. I think it is a combination of ADHD and the fibromyalgia with, brain fog. Because my mind just goes completely blank or I just feel like I've, reached the limit of information that I'm going to take in. I feel like I can't take in anymore."

Considerations to better support Aditi could include*

- Provide the opportunity for her to describe her fluctuating conditions, the frequency and impact of symptoms.
- Applications forms need to be provided in alternative formats. The paper form was not accessible for Aditi
- Due to fluctuating energy levels Aditi would benefit from some flexibility in deadlines for form filling.
- Aditi would also benefit from having someone support her in meetings

*Considerations are researcher generated based on participant feedback and overall findings.

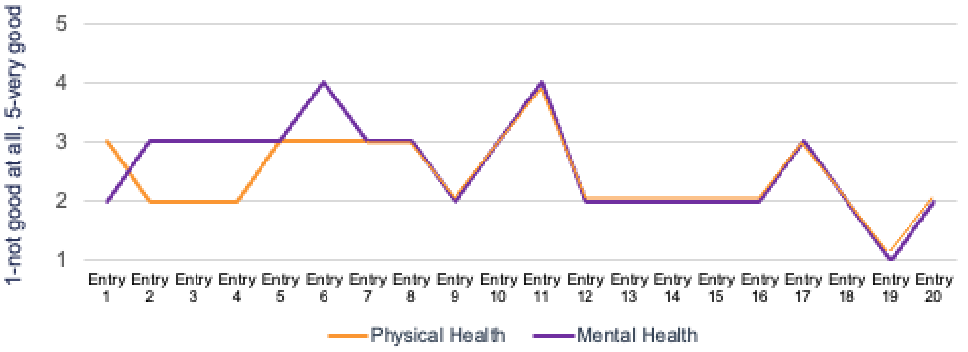
Impact of fluctuations

" I'm not even eaten yet. I've not even left my bedroom today. I've just been in this room, trapped in my body and brain."

"I'm just trying to reduce my stress levels, but there is only so much you can do? Yes, difficult. Very difficult. I've got a job interview this week, but I just haven't done stuff and the energy to do tasks and all sorts. I just haven't prepared, unfortunately."

Fatigue, pain and low motivation were constant; however Aditi made a significant effort to manage her condition. The 1-5 scale indicates a close relationship between her physical and mental health.

Diary study – physical and mental health rating
(1-not good at all, 5-very good)



Pen portrait: Meet Jacob

Experience of fluctuating conditions

Jacob is a young man with Tourette's, mobility and mental health challenges.

He experiences continuous tics and hallucinations with frequent worsening of symptoms. All aspects of his life are affected including his education, household, leisure and social activities.

Jacob has an unmanageable predictable condition. Despite understanding his triggers, the severity of symptoms is paralysing and often requires him to cancel activities.

The most severe known trigger for Jacob is stress. He has many others, quite a lot are known to him but unavoidable.

Experience of fluctuations

"Tic attack. Rather violent and intense one. Wiped me out and hoisted afterwards into bed."

"Can't move post tic attack so was hoisted off the floor and into bed. Legs still paralysed. Meds had to be put into my mouth by someone else to reduce risk of dropping them."

Considerations to better support Jacob could include*

- Give the opportunity to provide information on fluctuating conditions, their frequency and impact.
- Establishing trust is important to Jacob Provide an environment where he feels safe so he can best represent himself.
- It is important for Jacob that the assessors understand his conditions and how to conduct the interview in a supportive disability-confident manner.

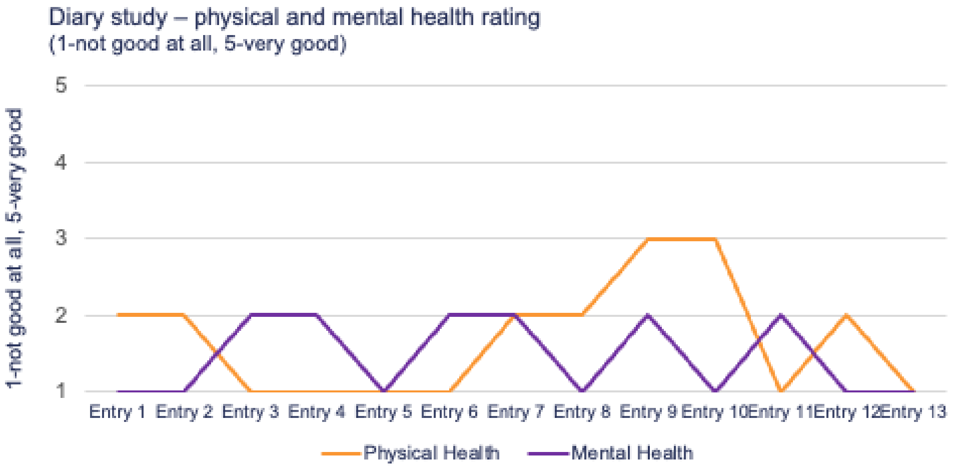
*Considerations are researcher generated based on participant feedback and overall findings.

Impact of fluctuations

"Anxiety got worse partly due to schizophrenia and also due to a visit to the theatre with constant vocal tics."

"I do not go out some days due to anxiety and schizophrenia symptoms."

Mental and physical exhaustion were continuously reported due to frequent tic attacks experienced over the 4-week period. Jacob regularly reported his mental and physical health at low levels.



Pen portrait: Meet Lucy

Experience of fluctuating conditions

Lucy is a woman in her 40s with multiple sclerosis and depression.

She struggles with multiple conditions that vary between severe body pain, vision challenges, low mood and tiredness. It's difficult for her to plan her days as conditions often worsen suddenly and without warning.

Lucy has an unpredictable and unmanageable condition. When symptoms worsen, she often doesn't know how long it will last and her current medication doesn't always help

Known triggers are lack of rest, stress and overdoing it. She also has unknown triggers.

Experience of fluctuations

"Quite a lot of fluctuating symptoms this week. Tingling in legs varying from severe buzzing to mildly irritating! Vision changing from eye to eye. Exhaustion being a major issue this week but varying in its intensity and debilitation. Mood has also varied. I thought we had got the new meds right but my mood has slumped somewhat as the week has gone on"

"Pain in legs, worse in left. Mental health not so good today. Feel quite sad and alone."

Considerations to better support Lucy could include*

- Support to better navigate and understand the application form which she found very stressful and complex.
- The opportunity to describe triggers and how outcomes and impacts vary for her
- Her symptoms can vary suddenly and without warning. Some flexibility in deadlines for form filling and timings/locations for the assessment interview would be an advantage.

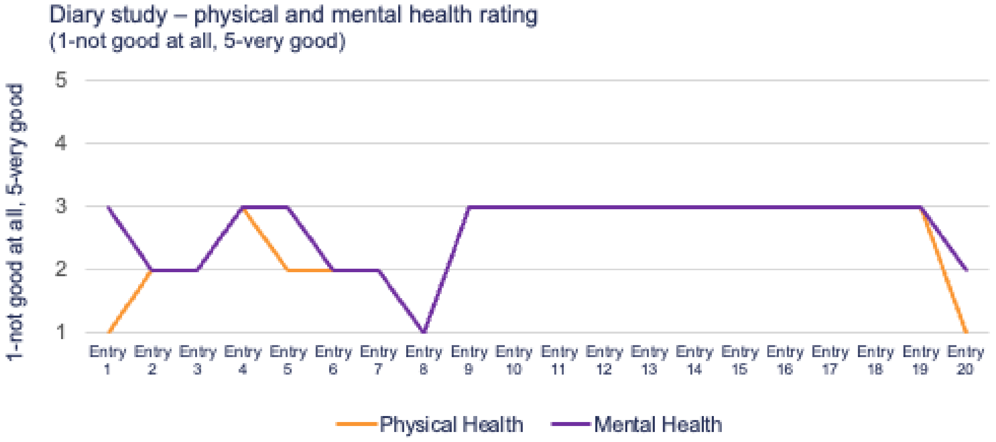
*Considerations are researcher generated based on participant feedback and overall findings

Impact of fluctuations

"Communicating is a huge thing…it can vary hugely. I am not too bad at the moment but even verbally, my face drops and affects the way I speak. I struggle to get to words I want to use, cognitive fog. It can affect everything. I might want to go to the shop and I might not even feel like I can do that."

"If I made a plan to meet for a drink – lovely to have things to look forward to. But I often can't do it. A reality of how to accomplish things, that is a huge thing."

Lucy didn't report feeling good mentally and physically during our diary study. Severe pain often impacted her mood, causing both physical and mental health to drop.



4.2.2 Triggers

A trigger is something that can bring on, worsen, or change the impacts of a condition. It can include environmental factors such as weather, personal choices such as diet or rest, and other external factors such as stress and anxiety. Triggers may be known or unknown.

This research found that triggers cannot always be predicted before or identified afterwards and the same trigger can lead to different outcomes on different occasions. Knowing that a trigger exists does not always mean that a fluctuation can be avoided.

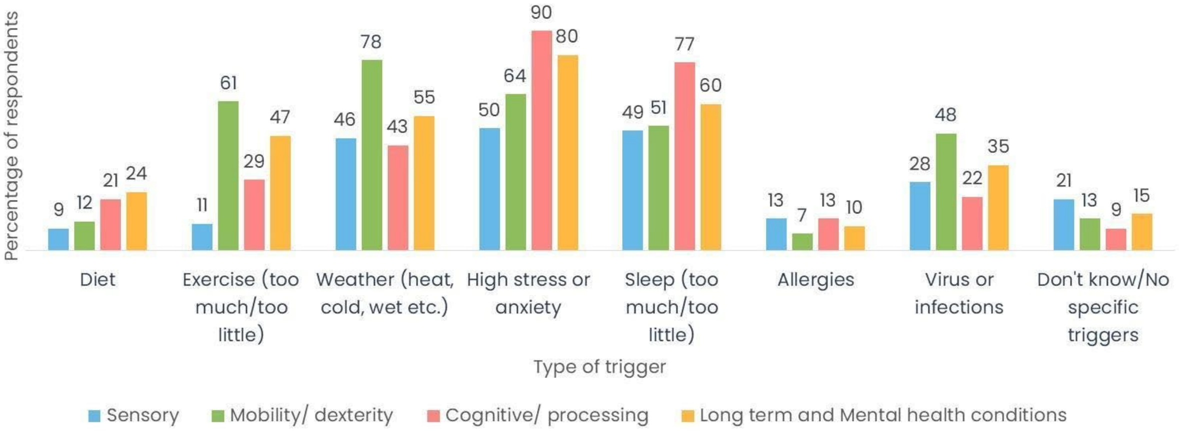
Participants talked about only being able to avoid some triggers to a certain extent, such as avoiding going out in certain weather conditions or not eating particular foods. In the diary they also mentioned having to undertake triggering activities even though there would be implications in terms of a potential flare up afterwards, for example having to knowingly overextend to complete work or household commitments, or having undertaken travel when the weather was likely to impact them.

> “It's a complete nightmare as I have very little control over what happens when exposed to what others see as normal. Frenetic, angry and noisy behaviour [such as you may experience in a crowded train station] that is unnecessary will trigger my condition."
>
> (Diary, Male, 55-64, neurodiversity and mental health)

> “I had to do some travelling this week, which made me very fatigued. This meant that when I got back I spent the following two days unable to do my normal daily activity.”
>
> (Diary, Female, 35-44, long term health and cognitive conditions)

In the survey the most commonly cited known triggers varied for each broad condition type. The most noted triggers overall were high stress and anxiety, unfavourable weather, negative sleep patterns, and too much or too little exercise (as show in figure 4.2). These impacted all groups to greater or lesser degrees.

Figure 4.2. Showing specific triggers that were mentioned by at least 5 percent of participants



Q. Are there any specific triggers that cause your significant changes related to [broad condition category]? You can choose more than one trigger or cause.

Base: All participants noting changes in reference to condition type; Sensory (76), Mobility/ dexterity (166), Cognitive (71), Long-term conditions and Mental health conditions (176)

See Appendix D for the associated data table. Identifying and observing triggers is an important part of living with a fluctuating condition as these can help with proactive and reactive management and experience of conditions. Even identifiable triggers are often not avoidable, or within people's control. Regardless of whether a trigger is known or not, and observable or not, fluctuations can still be difficult to manage.

4.2.3 Manage

Managing fluctuating conditions includes a wide range of activities that individuals may take to prevent, or reduce the regularity or severity of impaired physical, emotional, or cognitive capacity and capability that can occur during a flare up.

Many participants in the research were constantly vigilant about symptoms changing and how to avoid or minimise them. This may, in part, explain the relatively limited range of variation in how they felt both physically and mentally over the four-week period in which the diary study was conducted, despite experiencing fluctuations.

This section explores the range of management tools an individual may adopt to prevent, reduce, or counter negative fluctuations.

Variable knowledge, flexibility, or resources

Factors influencing the effective management of symptoms and impacts included knowledge, flexibility, and resources.

1. **Knowledge**: Understanding of a condition/s and how it manifests within an individual's specific personal characteristics and contexts. This includes,
    - Awareness and understanding of recommended medication, practices and approaches that have been helpful to others with similar conditions, symptoms, or barriers.

- Understanding of self and the participant's individual response to different management options and approaches.

The longer people have had a condition the more knowledge they generally have of its effects and how to manage it. This can include knowing how a change in symptoms feels earlier in terms of sensation or energy levels, understanding the likely regularity or duration of change.

> "Rest, really thinking about what I am doing and not going to try anything silly. Getting professional help this week…I hope it will have a positive impact."
>
> (Diary, female, 35-44, dexterity, cognitive)

Knowledge is also impacted by the level and quality of support a person has received from health professionals.

> "On Friday, I have a meeting with the medical nurse at the doctor's surgery. Discussed changes and how I might be able to reduce fluctuations with more medication."
>
> (Diary, male, 55 to 64, long-term conditions

2. **Ability / flexibility to adapt**: Flexibility to adapt to changing symptoms and capabilities when living with a fluctuating condition can help manage the resulting impacts. As described by participants, effective adaptability included:
    - moderation of exercise
    - flexibility of work (work from home, reduced hours or changed activities)
    - taking time to rest
    - reduction in other responsibilities such as at home, or
    - making and attending medical appointments.
3. **Resources and support:** Not all individuals have equivalent access to medical or broader community knowledge about options that may be available and suitable for them, the personal support, or resources to access better options for managing their condition.

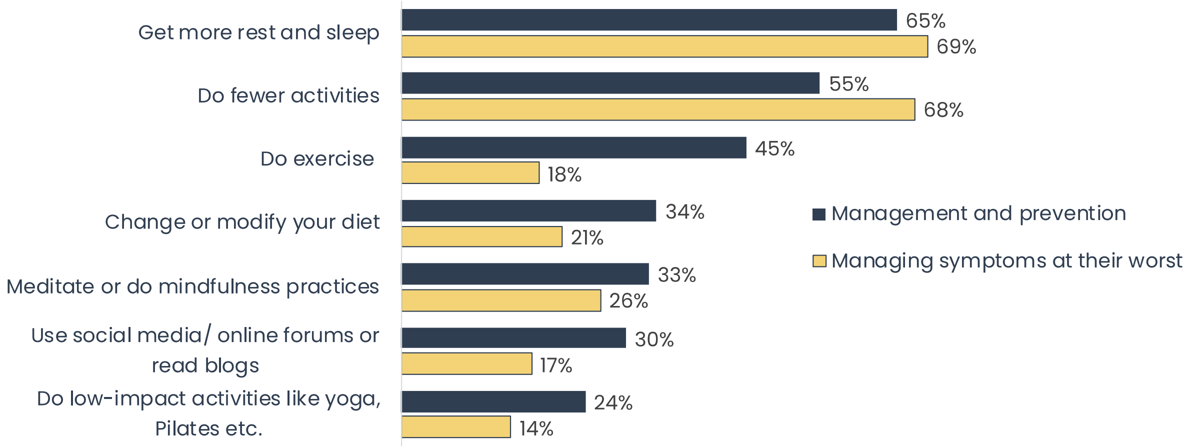
> "I'm worried about financial loss. What if I can no longer wear the hearing aids as they were very expensive?"
>
> (Diary, female, 55-64, long-term health conditions, hearing loss)

Management approaches

Through the research we learned about three major ways that people manage their underlying conditions proactively or in response to a flare up. These were self-care techniques, taking medications, or going to therapy and getting advice and support from health and non-health professionals.

1. **Self-care techniques:** In the survey, participants were asked to consider what management tools they used in relation to two contexts; ongoing management and prevention of symptoms getting worse, and in response to managing symptoms when they were at their worst. This was reinforced through findings from the diary study and interviews (see figure 4.3).
    - The most used self-care techniques were rest and sleep, moderating activities, and exercise.
    - Rest and sleep: rest was often the only way that people could cope with the flare up or episode and was hugely important for recovery. While rest was seen as an integral and important part of management it also came at a cost of having to miss out or scale back on day-to-day plans and activities. It was often used in conjunction with other approaches such as medication, diet and other self-care activities.
    - Moderating activities was also an important self-care technique both for ongoing management and when symptoms are at their worst.
    - Exercise was particularly important for prevention but not so helpful during a flare up.

Figure 4.3. Self-management approaches adopted to prevent and manage flare ups



Q: Do you personally do anything to try and manage your symptoms or prevent them from getting worse? and Q: When the symptoms you told us about are most severe, do you personally do anything to manage them in those times?

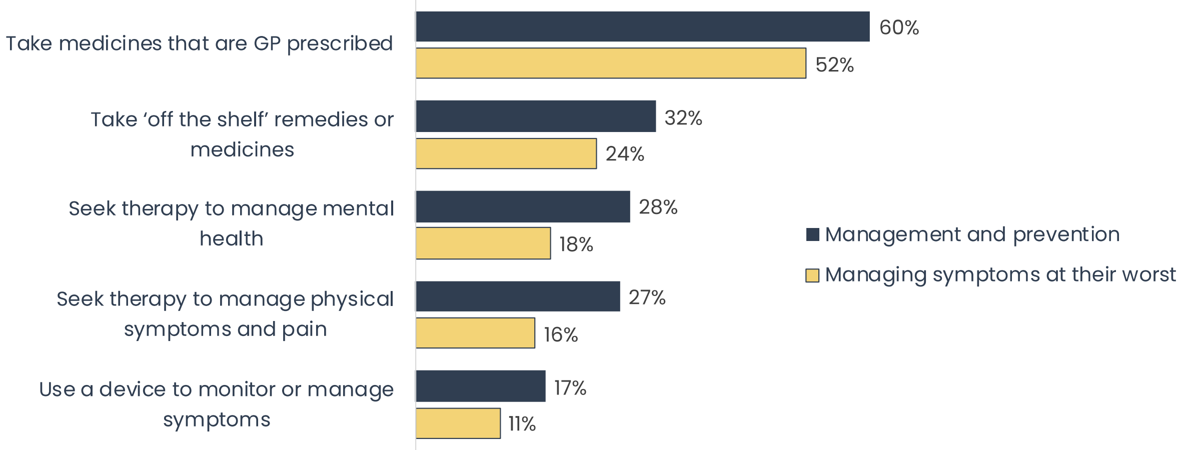
Base: all survey participant (297). ‘Other’, 'Don’t know’ are not shown.

2. **Medical and therapeutic management techniques:** In addition to self-management techniques, through the survey, diary study and interviews we heard that people engaged in a variety of medical and therapeutic support to manage symptoms. The survey responses (see Figure 4.4) highlighted that prescribed medications were the most common route to manage symptoms both preventatively and in response to the symptoms at their worst.

   > "Continue with new antidepressants. I am seeing my neurologist on Friday for yearly meeting."
   >
   > (Diary, female, 45-54, long-term health and mental health conditions)

   Other medical and therapeutic approaches to manage fluctuating conditions included off the shelf remedies or medicines, therapy, and the use of devices to monitor or manage symptoms.

Figure 4.4. Medical and health industry approaches adopted to prevent and manage flare ups



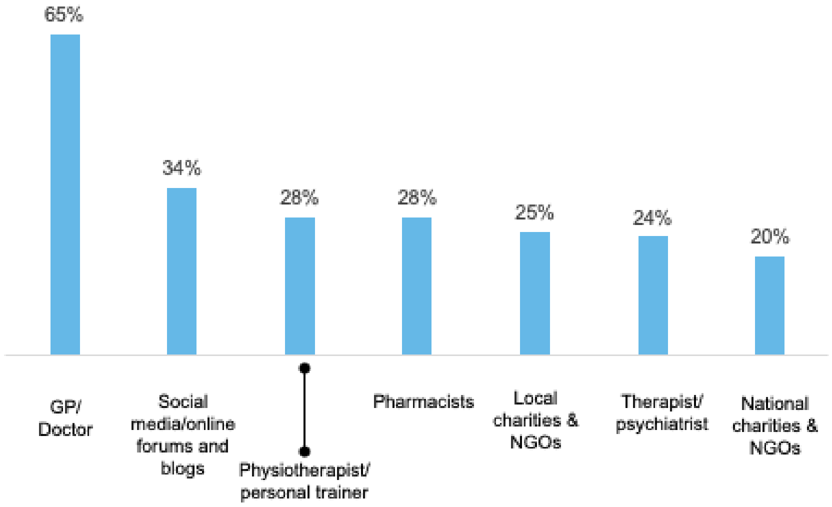
Q: Do you personally do anything to try and manage your symptoms or prevent them from getting worse? and Q: When the symptoms you told us about are most severe, do you personally do anything to manage them in those times?

Base: all survey participants (297). 'Other', 'Don't know' are not shown

3. **Engaging with health and non-health professionals**: In the survey, participants recorded their use of professionals to help support them in managing their conditions. This included doctors and other health professionals such as therapists, and other professionals such as support organisations and government organisations.

   In terms of ongoing management and prevention of fluctuations, the GP/Doctor was most commonly used (as shown in figure 4.5).

Figure 4.5. Use of professionals to help support fluctuating conditions



Q: Still thinking about managing your symptoms day to day, do you use any of the following health professionals or support organisations for support with your disability or access needs? Please select all that apply.

Base: all survey participants (297).

Fewer participants used health and non-health professionals when symptoms were at their worst, reflecting challenges that participants reported in having the physical or cognitive capacity to seek help during a flare up. Importantly, over a third of survey participants (36%) said that they did not get any support when symptoms were at their worst compared to just 12% who got no support during ongoing management and prevention.

This was also corroborated by entries in the diary study, where bed rest was sometimes the only solution to managing symptoms when they were at their worst.

> “I am at home in bed and in agony. Today is a really bad pain day and [I have] almost zero mobility.”
>
> (Diary, female, 65-74, mobility and long-term health conditions)

In summary, people with fluctuating conditions use a very wide array of approaches to mitigate the impacts of flare ups. The range and extent to which they can adopt management approaches declines when their symptoms are at their worst.

4.2.4 Outcomes

Living with a fluctuating condition means living with changing physical, cognitive and / or emotional resources. We have defined outcomes as the degree to which personal capability changes across these three inter-related areas.

Fluctuations reported by participants, particularly through the diary study, highlighted the degree to which personal outcomes could:

- Vary from one fluctuation, flare up or change in symptoms to another.

- Vary relative to the trigger; for instance, time of year and the weather can impact how bad outcomes can be.
- Generate multiple outcomes for each individual fluctuation or change in symptoms. On some occasions we noted negative physical, cognitive, and emotional outcomes in a single diary entry.

We have categorised the range and types of outcomes in terms of changes to physical, cognitive, and emotional capabilities as outlined below.

1. **Changing physical outcomes**

   These outcomes ranged from changing physical energy levels, functional capability through to pain. They impacted a range of areas of the body including internal systems and organs. In the diary study, many participants mentioned experiencing one or more negative physical outcomes.

   We categorised physical outcomes into the following areas:

   - Physical energy, including mentions of tiredness or fatigue
   - Pain or change in sensation
   - Blood sugar issues

   Pain was regularly mentioned by participants as a very disabling part of flare ups.

   > “So I’m at home, except now my back is very painful, it really hurts, I can’t walk at all and I’m dosed up on anti-inflammatories to try to ease it. It’s a day where I can’t do anything, my husband is having to do everything for me. I hate it.”
   >
   > (Diary, female, 45-54, mobility and long-term health conditions)

2. **Changing cognitive outcomes**

   Cognitive outcomes included reduced cognitive function and energy, dealing with the effects of lack of sleep and sensory overwhelm. Many diary entries noted negative cognitive outcomes across a range of themes which included:

   - Reduced cognitive function including confusion, dizziness, lack of focus, brain fog and memory.
   - No sleep or little sleep impacting cognition.
   - Sensory overwhelm.
   - Low mental energy.

   > “I have had a few very restless nights of sleep this week which has resulted today in me forgetting to take my ADHD medication. By the time I had realised it was too late to take, this also resulted in me missing two doses of my other medication due to my brain being fuzzy and busy. I am unable to concentrate.”
   >
   > (Diary, non-binary 25 to 34, cognitive, long-term and mental health conditions)

3. Changing emotional outcomes

Outcomes described by participants also included emotional frustrations and challenges of handling disruptive changes in symptoms, or the impact fluctuating conditions had on personal relationships and feelings of self-worth.

In the survey, participants were asked to discuss the challenges of having a fluctuating condition. A significant proportion of the responses related to emotional outcomes such as coping with changes, impact on relationships, self-worth and loss of independence. Please see Appendix D Table 3 for the full table.

In the diary study a number of participants mentioned negative emotional outcomes as a result of fluctuations in conditions over the 4-week period. Themes related to emotional outcomes included:

- Anxiety, stress or emotional distress
- Depression, low mood or sadness
- Coping with impact on or changing activities to fit with a flare
- Difficulty planning / cannot plan far in advance
- Impact on relationships / other people
- Loss of independence

Many people noted difficulty managing their emotions when symptoms fluctuate significantly and unpredictably.

> “Stressed! Overwhelmed! Unsure how to go on each day when things can be so varied.”
>
> (Survey, female, 25 to 34, sensory, cognitive, and long-term health conditions)
>
> “[It’s] frustrating and having to rely on others so losing independence. Not able to drive, shop on my own or go out to participate in social activities, asking for workplace reasonable adjustments is jumping through several hoops, not helped by workplace pressures and changes. [I] feel quality of life is poor and [I am] constantly tired…”
>
> (Survey, female, 55 to 64, mobility/dexterity and long-term health conditions)

4.2.5 Impacts

An understanding of the impacts from changing symptoms and capabilities provides key insights for the application and assessment process at DWP as well as how decisions are made.

We describe the impacts as personal changes due to a fluctuating condition/s in the ability to undertake any one of seven areas of daily activity including: leisure, social, financial, and household activities, travel, work, and education.

Fluctuating capabilities commonly disrupt short term plans and the ability to undertake activities at home, in work or education, and in an individual's personal life.

As described in Section 4.2.4, in addition to impacting today's activities, they have the potential to also generate future limitations. These are secondary or 'knock-on' effects that result from the chosen or required level of activities undertaken today. Individuals can exceed their limits in ways that leave significant deficits in resources such as energy, or which trigger new flare ups in symptoms that create future impacts.

Poor activity management on a given day can often create triggers for the future.

> "It makes me very cautious as to what I will consider doing. I do not want to get into situations that cause a flare up. It has a big impact on my confidence and makes my world smaller."
>
> (Diary, female, 25 to 34, cognitive and long-term health condition)

Fluctuating capabilities, especially those that are less predictable, are challenging to plan around. Unplanned disruption to desired activities creates a need for ongoing flexibility and intermittent support for many.

> "Today I have noticed that my dominant arm[11] has started to hurt. This has had a major impact on me today as it has prevented me from doing a few things. I had to get extra help around today to do some simple household jobs such as opening tins, preparing my tea, carrying things, and doing the ironing. I have no idea how this has happened as I have not done anything different. It has made me really upset as I do not like asking for help at all and I have had to rely on people to support me today."
>
> (Diary, female, 35-44, cognitive and long-term health conditions)

Impact of fluctuating conditions on daily activities

We explored the impact of fluctuating conditions in relation to undertaking the following seven activities. These aligned to those used by DWP in undertaking PIP assessments:

- **Leisure activities:** including events, exercise and in home entertainment such as TV and gaming.
- **Social activities:** including meeting friends and family, engaging with others face-to-face, making yourself understood.
- **Household activities:** including cooking, eating, self-care, managing therapy, washing and bathing, managing toilet needs, dressing, caring for children or others.

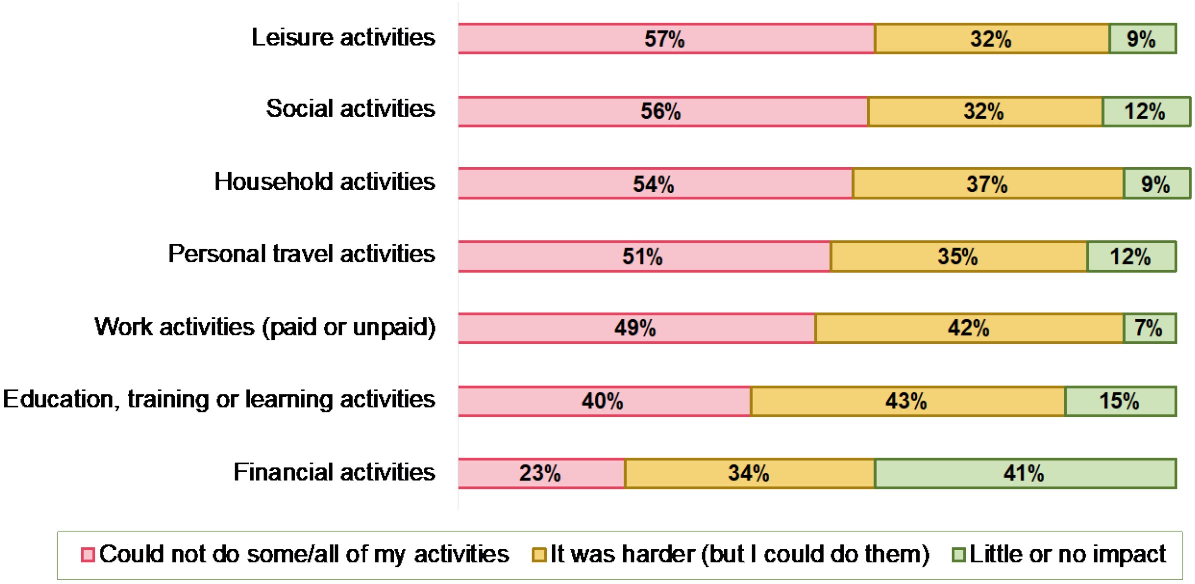
---

[11] Note: Her non-Cerebral Palsy (CP) impacted arm is her functional and strong arm. CP permanently impacts her other arm which has significantly reduced strength and control

- **Personal travel:** including driving or using other transport, planning or following a journey.
- **Work activities** (whether paid or unpaid work): including turning up to work, carrying out normal duties, organising and planning, meeting deadlines or targets.
- **Education, training or learning activities:** including communicating verbally, reading, writing, turning up to sessions, understanding and retaining information, organising and planning, problem solving, meeting deadlines or targets.
- **Financial activities:** including budgeting for the home, banking or managing bills.

In the survey a majority of participants reported that they had either not been able to do some or all of the activities within the categories defined, or that achieving them had been possible but harder to complete in the past two years as a result of having a condition that fluctuates.

Figure 4.5: Impact of significant changes in symptoms or conditions on key activities



Q: In the last two years, what impact (if any) have the significant changes in your symptoms or conditions had on your <u>[name of each activity] activities</u>?[12]

Base: All participants with responsibilities in these areas/all applicable Leisure 295 Social 297 Household 250 Personal travel 286 Work activities 250 Education and training or learning 205 Financial activities 279). Please note that activity responses do not always sum to 100 as “I don’t know” responses were removed.

---

[12] Each activity was also detailed in one clarifying sentence. For example, for financial activities it read “These could include budgeting for your home, banking or paying your bills.”

Detailed information of the impacts of fluctuating conditions on the seven individual activities, shown above, is in Appendix D

Key impacts described by research participants included reduced cognitive function, limited energy to engage in other activities and the impact on their personal relationships.

Reduced cognitive function has a significant impact on what an individual can get done in their day and how they can undertake it.

> “Everything takes so much longer now, and I cannot do as much. My world seems to be shrinking as everything takes so long and I cannot do anywhere near the amount that I did. Cognitive function can be so impaired on bad days I always need help to double check things I've done.”
>
> (Survey, female, 65 to 74, Cognitive and long-term conditions)

More commonly we heard how managing fluctuations in conditions could lead participants to have more limited energy to engage in other activities. Energy was described as a finite resource; where it is used on one activity it can affect someone’s ability to do other activities in turn either on the same day or on subsequent days. This was something that the current disability assessment process was not felt to capture very well.

> “It’s very difficult to plan anything or keep to a routine. Symptoms fluctuate so much that I never know how I will cope on any given day. I budget my energy and chores get done when I am able. My home has been very untidy which has led to me not wanting visitors. When I am struggling both mentally and physically the impact is severe.”
>
> (Survey, female, 55 to 64, mobility/dexterity, long-term health and mental health conditions)

Besides impacting the individual, the variance of fluctuating conditions can also impact their relationships.

> “[I] just go day by day. I worry about the impact on my children when I get so fatigued [that] I have to stop and lie down for an hour. They know why, but I know they wish I could do more with them.”
>
> (Survey, female, 45 to 54, cognitive and long-term conditions)

4.3 Key takeaways for DWP

1. Although fluctuating conditions can vary significantly in how they are experienced, we have identified a framework for understanding them that remains relevant across the spectrum of these differences.

2. This could provide a relevant framework for DWP asking about and understanding the experiences of those with fluctuating conditions through the application and assessment processes.

3. Underlying conditions may be more or less manageable. This can be due to the limits of medical knowledge, the limits of an individual's knowledge or resource constraints.

4. Some people may know what triggers their condition but be unable to avoid the trigger, such as changes in the season. Other triggers, once known are more avoidable. When people have co-occurring conditions, symptoms from one condition may trigger another.

5. Personal knowledge including learning what can trigger a change, professional support and management practices can build over time. People who have known about their underlying condition for longer may better recognise triggers and have a greater range of learned, tested and effective management practices that work for them. Those with newer conditions or undiagnosed conditions may have lower awareness of possible triggers and fewer management practices.

6. Fluctuations are easier to manage if they are more predictable, manageable and their most significant possible downturn is less severe. Multiple combinations of unpredictability, lack of manageability or severity can be disabling. Together these three elements inform the overall impact.

7. Describing the impacts of a fluctuating condition can be hard for an applicant, especially if they have had a condition for a long time. Variations in capability and limitations in daily life are their norm, not the exception. They may not have a good reference point for comparison.

8. When symptoms are at their worst, the range and extent to which people with fluctuating conditions can and do adopt management approaches declines.

9. Impacts on daily living activities have two levels that vary in timeframe. There are immediate limitations created by a flare up, and there are the future implications of undertaking an activity (on levels of pain, energy, emotional resource) despite having a flare up.

5. Experiences of DWP application and assessment

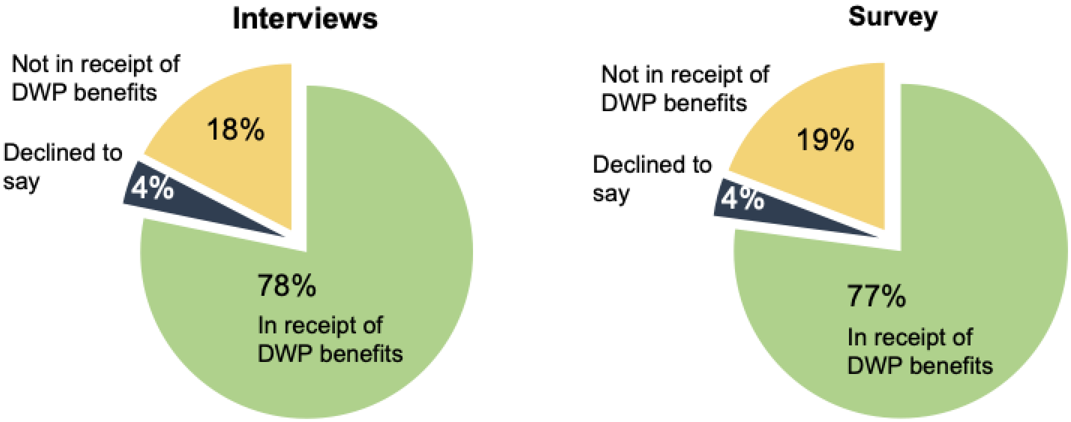
5.1 Introduction

In both interviews and survey research formats, over three quarters of participants were on DWP benefits, just under a fifth were not on benefits. See Figure 5.1 and 5.2. A few people in each declined to say.

Of those that received benefits, some had applied for them quite recently or were in the process of re-applying at the time of the interview. Others had not applied for a number of years, so their context of comments may not be reflective of the current DWP processes, for example describing mandatory in person meetings.

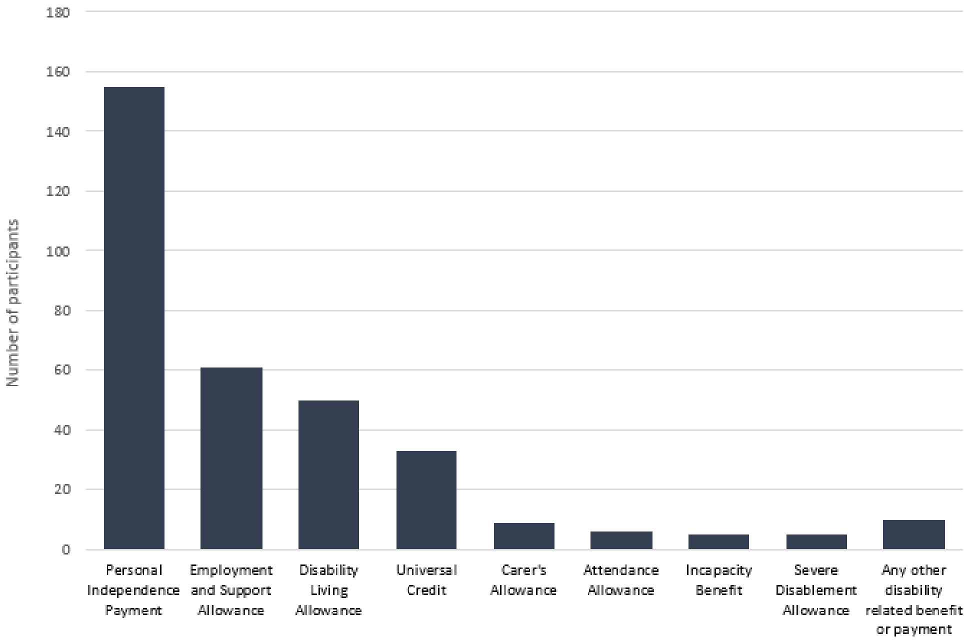
There were also a few participants who did not receive DWP benefits at the time of the interview but had applied for one or more benefits in the past. For context we have tried to add these relevant details to quotes as used.

Figure 5.1: Percentage of participants who did and didn't receive DWP benefits



Base: 49 interviews and 297 for the survey

Figure 5.2: Type of DWP benefits currently received – Survey participants



Base: 297 participants (some in receipt of more than one benefit).

Living with a fluctuating condition can make the application and assessment process for DWP disability benefits more of a challenge. Some challenges participants described are specifically due to the fluctuating nature of their condition/s. Some feedback received would be equally true for any applicant, or for an applicant with the same disability that they experience, even if it doesn't fluctuate.

We have tried to focus this report on those elements specific to fluctuations, or where it may be true to some degree for many, but the process is additionally difficult for those who have fluctuating conditions. This disaggregation of experience can be challenging, as the participant simply describes their experience. They won't always know which elements were more difficult due to the fluctuating nature of their disabilities.

Additional challenges related to fluctuating conditions when applying and being assessed for disability benefits:

- Variations in physical, emotional, or cognitive energy can make long processes such as an application more daunting to start and more challenging to complete relative to people with more stable capabilities. There is greater uncertainly across the relevant period.
- Time restricted processes such as the application or time-bound activities such as an assessment interview (online or in person) can be more difficult for people where future fluctuations are hard to predict or plan for.
- It can be hard to communicate variable implications of fluctuating conditions through the process relative to conditions that are more stable.
- Applicants may be more fearful, relative to those with more stable disabilities, that they will be misunderstood and unfairly assessed. They are conscious that they

have some occasions when they have significantly more capability than other times, and don’t wish to be assessed by a moment in time that is not representative.

5.2 Feedback on the application and assessment process

5.2.1 The application process

All four categories of feedback noted in Section 5.1 were issues for both the application process and the assessment for applicants with fluctuating conditions. We will briefly describe each of these as they relate to the application process.

A daunting application process due to length and complexity of form

Through the depth interviews we heard from participants who had found the application process “daunting” to start and “draining” to complete.

Although this may be true of any applicant, for those with fluctuating conditions anything that takes place across a longer period of time (e.g. self-completion of an application form) risks greater uncertainly in relation to disability-related disruptions. A flare up may impact the applicant’s ability to complete the process as planned. It could increase their specific accessibility requirements (such as vision, focus or dexterity), or limit their mental or physical energy to complete the forms. Equally stress around the application process may itself be a trigger, particularly for those where heightened anxiety is a common trigger.

> “The form itself is really daunting. Confronted with it the first and second time it made me feel so depressed and pressurised. I contemplated not completing it. So bad for my mental health…It is designed to put people off from the very onset.”
>
> (Interview, female, 45-54, mobility, long-term and mental health condition, currently on PIP)

Time-restricted activities

Time limits to complete the application make the activity more challenging. It means that it may not be possible waiting to wait for a flare up to pass.

One participant described that the application was hard to complete due to intermittent fatigue, so they had to spread the completion of it over a period of time. The deadline to respond then became stressful.

> "It took me a few times to go back to it and actually finish it off. And then of course I had to reread it again to make sure I'd written it correctly. So that [time limits] makes the process worse. That’s [what makes me] more stressed."

(Interview, male, 55-64, sensory, mobility and long-term conditions, currently on PIP)

It can be hard to describe fluctuating conditions and changing impacts

Participants mentioned that application questions could be improved for people living with fluctuating conditions. They could be designed to allow applicants to more easily self-describe the varying nature of their abilities and potential consequences of undertaking activities that are possible, but then have implications on energy/capacity to undertake subsequent activities.

The way the questions are currently written made it difficult for applicants to give suitable answers, because they felt that the questions were asked in a limiting or binary way.

> "The wording didn't encourage you to describe the variability or fluctuations."
>
> (Interview, female, 65 to 74, long-term and mental health conditions, regarding PIP)

> "The phraseology in the questions are looking for very black and white answers… they don't ask if they're happening all the time… The wording didn't encourage you to describe the variability."
>
> (Interview, male, 55 to 64, sensory and long-term health condition, regarding PIP)

Participants also noted a perceived emphasis on physical rather than cognitive or mental health symptoms and some participants stated that did not enable them to provide the full breadth of information on their conditions, particularly in the ways they impacted their cognitive or emotional capabilities.

Concerns that their needs may be misunderstood

Applicants often share their more impacted days or periods in the application and assessment, for fear of having their challenges misunderstood. There was a concern that assessors would use evidence of more positive or less impacted days against them.

> "I've always put a worst-case scenario in everything I've put. I've never said Monday, Tuesday, Wednesday, Thursday, Friday I'm in agony but Saturday, Sunday I'm OK. Because once you start doing that, then you're sort of leaving yourself open. I don't know if that's true or not."
>
> (Interview, male, 55-64, sensory, mobility and long-term conditions, currently on PIP)

It is complicated to describe the implications of fluctuating conditions across the 7 activities. Someone reviewing the application needs to be in a position to determine how often their condition affects them, and how significantly it impacts them at a point in time and across time. This is complicated, especially if fluctuations are frequent, of varying severity, intersecting or otherwise challenging to describe for the applicant.

Many applicants were concerned that the extent of the overall impact of their condition/s would be misunderstood. This was also associated with a lack of trust in the way DWP makes decisions.

> “The process has absolutely no space for recording and space for changing symptoms. However, I also feel that I would be very scared to document changes and fluctuating conditions as [if] the DWP hear you can do something maybe once every few months and they then think you can do it all the time and therefore score zero on that bit of the assessment."
>
> (Interview, male, 25-34, mobility, cognitive/processing, long-term and mental health conditions, describing PIP)

5.2.3 The assessment process

Through the interviews we heard of concerns about DWP assessments (predominantly PIP) that centred around difficulties applicants have managing the current process due to their condition/s, fears of being misunderstood, and a desire to be fairly assessed in line with their experience with a fluctuating condition/s.

Concerns raised described practices experienced last time they were assessed. Some of these practices will have been changed since then.

Process complexity and difficulties

A number of participants described a lack of flexibility in the format[13] and timing of the assessment. These elements were particularly difficult for those with fluctuating conditions.

Getting to and managing in-person meetings was complex for many. Travelling to meetings can be a variable challenge (easier to do on some days than others) depending on the current state of a participant’s condition/s for some applicants. Travel can also be a trigger for some people, increasing the risk of a flare up of symptoms. Some people had a preference for online or phone options to have been offered (noting they had been assessed when this wasn’t an option).

One man with a relatively unpredictable condition that meant he could have a flare up of symptoms requiring him to be close to a toilet. He noted,

> “I was trying to explain to the job centre about my [conditions] but they still wanted me to go in. Even with the toilet there it’s still 35 minutes on the bus. It was hard to me to handle that mentally.”
>
> (Interview, male, 35 to 44, Long-term conditions, discussing Work Capability)

Time-bound activity

Many participants wished for flexibility to reschedule an assessment in case they needed to change the date of the assessment due to a flare up limiting their ability to attend.

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[13] Assessment channel changes are available when requested by applicants, but no participant mentioned that they had been made aware of this.

It can be hard to describe fluctuating conditions and changing impacts

Fluctuations or changes in symptoms sometimes made sharing information in the assessment more difficult to manage for some applicants.

For instance, participants mentioned it being difficult to communicate, process information or answer questions during the assessment when symptoms were at their worst.

Reduced cognitive capability such as from exhaustion, brain fog or anxiety can change the ability to respond. Some participants also had variable communication capabilities when symptoms were flaring.

> "Communicating is a huge thing…it can vary hugely. I am not too bad at the moment but even verbally, my face drops and affects the way I speak. I struggle to get to words I want to use, cognitive fog. It can affect everything."
>
> (Interview, female, 35-44, long-term and mental health condition, discussing PIP assessment)

Another participant with chronic pain and ADHD discussed how they were "low on spoons" [short on energy] when going through the PIP assessment. They described that they had found it hard to articulate their thoughts and feelings clearly.

Concerns that their needs may be misunderstood

In the assessment part of the process, as in the application, there were significant fears of being misunderstood due to the fluctuating nature of the condition/s and the variable impact on day-to-day living.

> "I think the fluctuating bit is almost like you can't focus on that because it's like saying well how many lovely sunny days are we going to have in the next six months?"
>
> (Interview, female, 45-54, long-term conditions, discussing PIP assessment)

Some participants felt that the final report contained a lack of clarity about how decisions were made. This increased fears that they had been misunderstood during their assessment and the impacts of their fluctuating capabilities had not been fully understood and assessed in an equivalent way relative to more stable conditions.

> "I think it's me knowing, or whoever knowing, that whatever you say to him is going to be taken in context rather than taken out of context and expanded on…like I was saying about the good times, they'll think about the good times. I'm thinking about the bad times, you know, good times are just a bonus."
>
> (Interview, male, 55-64, long-term conditions, discussing PIP assessment)

Participants felt that questions asked in the assessment did not effectively seek to understand and capture changes in their symptoms, outcomes, and impacts.

- It was difficult to discuss impacts when questions were based on a fixed point in time.
- It would be an advantage if some additional context could be given for answers; for example, rather than ‘can it be done’, looking to understand whether activities can be done safely or effectively, if this capability changes when symptoms are at their worst and if doing these activities is likely to trigger a negative change in symptoms (and hence are usually avoided).

> “[I] don't think that there was really anything much about fluctuations, not from my memory. It just seemed like some person, who had been contracted was just basically reading a list." (Interview),
>
> (Interview, female, 25-34, cognitive and long-term conditions, discussing PIP assessment)

Assessor skills and style were also problematic for some participants. Some participants noted that assessors,

- Were unprepared for the assessment. Some had not read the application form, which was frustrating for those who had struggled to complete it.
- Some participants felt that they had been asked questions which they felt were unnecessary and unrelated to the assessment.

> “They ask some math questions don’t ask me why. The assessment itself didn’t give me a chance to represent the impact.”
>
> (Interview, female, 25 to 34, mobility, long-term conditions, discussing PIP assessment)

- Did not demonstrate good listening skills. Some showed a lack of empathy or respect for the applicant.

> “I think it's just getting people that will actually listen to you. What you're actually saying to them.”
>
> (Interview, male, 55 to 64, long-term conditions, discussing PIP assessment)

5.3 Potential improvements for the application and assessment process

In this section there are some suggestions that emerged through the research to address challenges outlined in the benefits application and assessment processes.

From the engagement with participants, we identified four potential areas where DWP applications and assessments could be strengthened, informing both the process and how decisions are made. These ranged from adjusting the questions and guidance for conducting disability assessments to introducing greater flexibility in the process and providing additional support and guidance to claimants.

5.3.1 Enhancing questions asked in disability assessments

Many participants believed improvements to the questions used in the DWP application process (application and assessment) would enable them to better explain their conditions and the impacts of these fluctuations.

Suggestions from participants covered areas that questions and assessor guidance could take into consideration. These included:

1. **Help applicants describe relevant variable impacts**: Go beyond a ‘moment in time’ measurement of function. It may help to use the fluctuation model outlined in this report to more fully understand aspects of living with a fluctuating condition/s and how it influences their daily life, including:
    - Understanding underlying condition/s that impact the applicants' health and ability to undertake daily living activities, specifically how manageable is the condition/s and predictable are flare ups or changes in capabilities.
    - What are the known triggers such as low or no sleep, or seasonal triggers such as weather that often precede flare ups. Are there any common to fluctuating conditions that claimants can be prompted to report.
    - What are the range of approaches known to the applicant that they can apply to manage or mitigate the impacts of a flare up.
    - How do changes impact personal capabilities
        i. Physical outcomes such as pain levels, fatigue, or energy levels.
        ii. Cognitive outcomes such as sensory overload, processing or memory challenges.
        iii. Emotional outcomes such as anxiety, depression, or emotional resilience / mental health variations
    - What are the implications of the changing capabilities on what they can do, both in the moment and as a consequence of activities they either need to or choose to undertake. Consider performance aspects such as how long a task takes them and how well they can complete a task. It is often not a simple yes/no answer.

2. **Support people in identifying the ‘majority of days’**: Current guidance is to account for descriptors that are applicable on over 50% of days, across a 12-month period. This can be quite challenging for people to understand or to assess themselves in practice.

    As fluctuating conditions have differential impacts over time it may be helpful to adjust the ways in which questions are asked to help people express the amount of good and bad days they experience, what effects this and what effect this in turn has on what they can and can’t do.

In the in-depth interviews participants were specifically asked about the activities that currently form the basis of assessment questions and options for determining levels of function i.e., household activities, work activities etc. However, it was difficult to answer questions about level of function that do not include a recognition of this potentially changing across a relevant reference period. As noted in the section earlier on frequency of changes (Section 3.3.1), a relevant reference period may vary from one applicant to another.

For many participants activities could be:

- Achieved on some days and not others.
- Achieved without triggering further symptoms (such as paid, stress or significant energy decline) on some days and not others.

Possible frames of reference for assessment options were discussed through the in-depth interviews for the following. We explored three options:

- **whether the ability to do an activity varied throughout the day**. Some participants noted that this was the case and would be welcomed.
- **whether activities can be achieved on good and bad days**. This worked for some participants. Others thought they would struggle with how to position this as days were so varied.
- **describing a typical day**. This was not so well received. Many noted that there was no such thing as a typical day and that no two days are the same.

> "It would be good if they asked more about how often it [my specific access needs] fluctuates and what the effects are of those fluctuations. If they asked what I have achieved over a week or two weeks it would be a reasonable time frame to get an idea of how much assistance was needed."
>
> (Interview, female, 25-34, wheelchair user, sight loss, long-term health conditions)

5.3.2 Provide greater flexibility in the application and assessment process

Participants noted that the requirements experienced in completing different DWP application and assessment processes could be improved to make it easier to complete an assessment more accurately, accessibly and confidently.[14] It could also reduce what was felt to be unnecessary effort, friction and stress induced by processes they had encountered.[15]

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[14] PIP was the most commonly experienced application and assessment process experienced. See Figure 5.2 for the balance of application formats experienced, for survey participants.

[15] It should be noted that as participants were reflecting on processes that they experienced last time they applied for benefits, some of these processes and practices will have since been updated.

This may be true of any applicant, especially those with access needs, assistive technologies or adaptive approaches which require accessibility of the application and assessment processes to have been considered and provided.

For those with fluctuating conditions, the uncertainly of what functional, cognitive or emotional capability they may have tomorrow or next week, can make completing a lengthy and complex application process additionally intimidating and potentially more difficult. This is particularly true if it is a time-bound process or there is a time-specific element within the process such as an assessment date.

Two improvements in terms of flexibility of process could specifically help applicants with fluctuating conditions.

1. Increased flexibility in time

Time limits to complete applications created barriers for some participants.[16] Suggestions include:

- The potential for receiving time extensions may need to be better publicised so that it is known that applicants can get extensions, and under what conditions or circumstances.
- Providing more flexibility in the timeline up front for some who have conditions that are likely to need more than the usual deadline. This may be due to anticipated challenges such as seasonal health decline, a need to access professional or personal support for completion (see 5.3.4), or where the timeline may itself trigger a flare up, making time-limited completion more complex.

Some improvements in relation to administration of assessment meetings were also raised that reflected issues previously experienced:

- More flexibility for changing interview dates was requested, to better manage situations when there is a fluctuation in condition.

  > “When I’m not well the ability to articulate how I feel is a different thing to how I am feeling. [Comparison was made with job interviews]. I was “low on spoons.”
  >
  > (Interview, female, 25-34, long-term health condition, cognitive condition, experience of PIP)

- Offering different assessor meeting formats for those with a significant preference or requirement for online, on phone or in person. This was especially noted by those who find travel to meetings particularly difficult and likely to trigger fluctuations or a format such as phone-based interviews not to work for them. We are aware this is already offered to a greater degree now than it was at the time some of the participants last experienced an assessment.

2. Increased accessibility and adaptability of formats

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[16] Although extensions may be asked for and provided by DWP for applications, no participant mentioned that they had been aware of this, applied for or received an extension.

It is important to offer a range of formats and requirements across the full process that will be accessible and inclusive of people with a very wide range of physical, cognitive, and emotional capabilities.

Although this is true for all applicants, those with fluctuating conditions may not have the adaptive skills or assistive technologies as those with more consistent and predictable access needs. Those with newer or degenerative conditions may also be underinvested in adaptive solutions or less adept at navigating communication formats or environments that are not accessible.

More accessible and inclusive options for the application form could include,

- Ensuring that there are a range of well designed, coded/published formats for the application form, including digital and paper. These should be made as accessible as possible by working to the standards and guidelines, for communities with different access needs. This will ensure that they work for people to manage independently, including those who use more and less sophisticated assistive technologies and adaptive approaches.
- Providing and showcasing the flexible format options available that applicants may not be aware of. Some participants were unaware that there were alternate formats available (they may not have been at the time of their last assessment). As a result, they found the format available more difficult to manage than if they had an alternative.
- Reducing the length of the form and simplifying the complexity as far as possible. Some participants mentioned it was ‘draining’ and breaks were needed to recover, particularly if a condition fluctuated in the time period that they were completing it. For some, the perceived and actual complexity of the process itself was sufficient to be a trigger for a decline in mental or physical health.

5.3.3 Upskill health disability assessors and other staff

A critical element of claimants’ confidence in, and experience of, the benefit application process was their engagement with DWP staff. Primarily through the assessment part of the process.

There was a view amongst participants that it would be beneficial for all staff involved in disability application and assessment processes to be more aware of the implications of the different needs of applicants with fluctuating conditions.

Staff induction and training could include helpful references to and information about those with varying needs from fluctuating conditions. This could be incorporated into broader disability confidence and inclusive service design or delivery training.

For front-line staff, particularly assessors, there were a number of specific suggestions from the participants. These included ensuring that assessors have,

- Prepared well before the assessment, such as reading the application form and thinking about how an individual condition does or might fluctuate, outcomes in terms of changing capabilities and impacts on daily tasks reported so that they are prepared to ask relevant questions.

- Active listening skills, and respectful inclusive communication capability and attitude so that the applicant feels they have the space to share their specific relevant experiences, especially how they vary and the implications of that. Adding in an element to the more broadly-based disability awareness and engagement training that gives assessors greater confidence discussing fluctuating conditions would help create a meeting that is less stressful and more productive for both the assessor and applicant.
- A source of knowledge and understanding about fluctuating conditions that assessors can reach to as and when relevant for an assessment. This could include understanding what are the more common underlying conditions that fluctuate, considerations around co-occurring conditions and needs, differing levels of manageability or predictability and some understanding of the connected common elements of fluctuation cycles outlined in this report. It could even have some case studies to help them understand different personal circumstances and how they may affect the assessment.
- Interview participants also suggested that people, across a range of disabilities including fluctuating conditions be involved in assessment tribunals.

These changes could do a lot to address current gaps in trust and confidence in the DWP process and assessment experience, while reducing unnecessary friction and stress.

> "It is about building confidence that DWP will take all aspects of the reported impact and not use the positive fluctuations as evidence against you."
>
> (Interview, male, 45 to 54, long term condition, experience of PIP assessment)

5.3.4 Provide additional support and guidance to claimants

Additional support and guidance for applicants was noted as being potentially very helpful.

Either guidance documentation or support from a benefits advisor could help applicants know what is expected to complete the closed and any open-ended questions, especially as they relate to fluctuating capabilities.

> "Having all of the information online and making it sharable directly would be very helpful."
>
> (Interview, female, 45-54, mental health and long-term health condition, had applied for Universal Credit and PIP)

DWP could provide greater clarity by developing guidance documentation that supports applicants as they are navigating the process. It would:

- Be accessible in a range of formats.

- Showcase what is expected to be answered, described or evidenced for each question.
- Help those with fluctuating conditions and impacts on their lives know how to describe their situation more easily.

A number of participants felt that they needed in-person support (either digitally provided or face-to-face) to fill in the application form helping with the interpretation of questions and understanding any available guidance. Some had used informal contacts or charities or local organisations to help them do this in the past.

The preference for source of support varied. Some participants would prefer this to be provided by DWP. Others would prefer additional support to be provided by local or national disability organisations. Irrespective of who provided the service, it was preferably with a contact who understands their conditions, or at least conditions which fluctuate.

Whether new services are added or not, participants mentioned that they would like better signposting to help raise awareness of that which is already available.

Participants believed the introduction of additional guidance and support would enable them to complete the application more successfully, while reducing friction and stress induced by the process.

5.4 Reviewing three White Paper initiatives

Participants were introduced to three new potential initiatives that could improve the process for applicants and they were asked for their opinion about each. Each was outlined in the DWP Policy Paper “Transforming Support: The Health and Disability White Paper”, March 2023.[17]

The suggested initiatives were described in the following way in the interview:

The Health Impact Record: There are proposals to give people the option of recording the changing impact of their health condition(s) over a period of time, rather than only at the point of assessment. This would be done in something called a Health Impact Record. The Health Impact Record would also allow you to provide evidence from your health and social care support networks.

Use of evidence: There may also be ways to improve how people’s medical evidence is collected, submitted, and used during the assessment process.

Specialist assessors: DWP are interested in how they can match a person’s main health condition to a specialist in that health area.

5.4.1 The Health Impact Record

The Health Impact record is under development, and although ‘a structured way to present evidence over a period of time’ lends itself well to a diary, it may not take this

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[17] Transforming Support: The Health and Disability White Paper, 16 March 2023, ISBN 978-1-5286-3687-2 https://www.gov.uk/government/publications/transforming-support-the-health-and-disability-white-paper

format. The broad concept of the Health Impact Record elicited a positive response from many participants, but came with caveats about its design, process, and use.

Positive reactions to the concept were related to how it could give individuals a better mechanism for discussing conditions that fluctuate or change over time, particularly in terms of discussing outcomes of changes and impacts related to activities.

One participant for example mentioned that it seemed positive and that he would just like to make sure he could upload voice notes with his camera off. Others directly contrasted it to the current process.

> "Sounds a lot better than the current process if you are looking at different periods of time. Especially for chronical illnesses."
>
> (Interview, Female, 18 to 24, anxiety, ADHD, experience of Universal Credit assessment)

Discussions explored the logistics of managing the Health Impact Record:

- Participants reflected on the ideal length of time the record should last for to enable them to best record changes in their conditions. Thoughts varied from a week to a few months. It was raised that a 'one size fits all' approach should be avoided, and the relevant length of time should be agreed with each claimant.

> "That sounds okay, but it depends how it would be done and how often. It would be positive if you are able to report a change or if you are having a particularly bad day. Maybe a month would be a good timeframe."
>
> (Interview, female, 44 to 54, long-term health condition, experience of Universal Credit and PIP assessments)

- Reminders to complete the record, access to support for queries, and guidance throughout the task for those who might need it were also mentioned. For some with memory challenges the Health Impact Record was seen as a potential benefit, enabling people to record changes at the time they occur.

> "I think if it's quick and easy to do and to define what you mean by changing, I think that could work well. I know for me it would work well cause I'm just not a writer and the short-term memory means I forget things. So if I can do something very quick in a format I'm already using like WhatsApp, then yeah, I think that works."
>
> (Interview, female, 35 to 44, cognitive and mental health condition, not currently receiving DWP benefits)

Participants also noted some concerns about the idea:

- Some people may be uncomfortable writing about sensitive symptoms and conditions and preferred a one-to-one setting.

- The task of 'diarising' comes easier to some than others depending on processing and writing skills, and it also depends on the type of health conditions. For instance, some participants felt it might be easier to discuss physical health rather than mental health in a diary. Others noted that writing about their limitations could be depressing.

> "I'd do it if I had to, but if I had to do the detail and record everything that happened as it happened, it would be depressing beyond belief."
>
> (Interview, male, 45-54, cognitive, mental health and long-term health conditions, limited dexterity, experience of PIP assessment)

- Fluctuations in conditions can make it difficult to fill in entries on some days. Flexibility in when and how claimants add entries was mentioned as important.
- Participants mentioned that the creation of a Health Impact Record should be optional, and that opting out should not disadvantage the individual in any way.
- There were worries that including a Health Impact Record in the application process might delay getting an assessment, and in turn, the receipt of benefits.
- Accessibility of diary making was discussed in terms of the format used i.e., the degree of technology capability that may be needed if this were to be digital and also the accessibility of the software, including that it works successfully with assistive technology.
- Participants expressed concerns about how DWP would interpret and assess the content of a Health Impact Record and were concerned about how the information might be used as a justification for not awarding a claim. This is likely an extension of broader trust issues than specific to the Health Impact Record.

> "I think it's interesting because if people are frustrated with the hour assessment and they don't think that they're being fairly assessed because it's not a true representation of them at that particular point, then you know, perhaps there is the justification….they might feel more confident that if they have a longer period to disclose or showcase the fluctuations… people might feel quite positively about that... but you're gonna get a lot of people that are like, wow, hang on a minute. It's really unfair for me to spend the next two to four weeks providing it when Joe Blogs down the road with his physical condition is done in an hour."
>
> (Interview, male, 25 to 34, mobility/dexterity and long-term condition, not currently receiving DWP benefits)

Learnings from the diary study research element

A diary study was used as a methodology in this project[18] and some lessons were learned which are applicable to the concept of the Health Impact Record. At the end

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[18] For the research purposes of this study participants were being acknowledged for their time and supported by an experienced disability-inclusive researcher, with safeguarding processes in place and interviewed after. For an application process which may result in either a positive or negative benefits award, the process of documenting may be less positive and more stressful.

of the diary study participants were asked what worked well and what could have been improved. While a different mechanism and purpose to the Health Impact Record, there are some parallels in the processes that are worth reflecting on.

Some of the shared experiences at the end of the study included,

1. Greater personal awareness

Investing the time in noting down changes helped some participants better understand the challenges and barriers they faced in terms of how their condition changed or fluctuated over time in frequency, duration of changes and links to triggers.

> “I've been more aware of my mobility declining as I'm now focusing on it for this study. When you live with something on a day-to-day basis you don’t really notice the changes until somebody points it out. I've also realised that my condition is never the same, on a daily basis. Some days I've woken up feeling fine and raring to go, others not so much. I realise I need more of a routine and am now determined to make that happen.”
>
> (Diary, female, 55-64, long term condition)

It enabled some participants to be more aware of the outcomes and impacts of fluctuations.

> “It has been a real eye opener as it has made me really think about how I am feeling or how much pain I am in. I have always just got on with life and it has allowed me to reflect on everything. I have also opened up more about how I am feeling.”
>
> (Diary, female, 35-44, mobility and dexterity)

> “It is interesting to reflect on how your 'normal' condition affects your daily routine and work. With it being a fluctuating condition, it does, therefore, feel very repetitive in both how you feel and actions, but it also makes you realise that it affects your work.”
>
> (Diary, male, 55 to 64, long-term conditions)

2. Ease or difficulty using a diary approach

Some participants struggled downloading and using the software selected for the research**.** For these individuals, we provided options to send content using Word or WhatsApp.

Participants also had direct access to researchers who fielded queries and offered alternative formats if preferred at any stage.

Detailed guidance was needed on both how to fill in the diary and how to use the software. Reminders were also sent to participants throughout the four weeks.

Many participants found it easier to write the diary as time went on. However, some participants felt overwhelmed by the process or noted feeling depressed when documenting their symptoms.[19]

3. Appropriate level of detail

Some participants worried that their entries may not have been detailed enough to accurately represent the outcomes and impacts of their fluctuating conditions.

Implications for a potential Health Impact Record approach

If the Health Impact Record was recorded over a period of time it may increase personal awareness of the condition and its impacts. This could make it easier for claimants to describe the impacts of their fluctuating condition/s more clearly through an application and assessment process. However, completing entries over a period of time can be stressful and trigger poor mental or physical health outcomes for some people. It effectively raises the potential of exacerbating or introducing additional vulnerabilities. Others may not have the energy, especially if experiencing a flare up. It may be best offered as a voluntary rather than mandatory option, and with flexibility in when entries are made across the reference period.

There are also a range of design choices that could make a Health Impact Record easier for more people to complete. These include considering,

- Ensuring adopted software has good accessibility.
- Providing alternative formats for those without mobile or computer access and those less digitally confident or comfortable.
- How users get support and who could provide the support.
- Providing reminders to claimants across the reference period.
- Alerting a user as early in the reference period as possible if they appeared to have misunderstood the guidance given on what information was needed.

5.4.2 Direct supply of evidence from GPs or the NHS

There were some positive reactions to the concept of GPs/NHS sharing data directly with DWP in support of a claim. Automatic data sharing (if agreement is given) might help reduce the burden on the claimant to collect and provide the required evidence. Medical evidence to support a claim was also viewed as a valuable contribution to the application process. If there is specific evidence of fluctuations in a condition from a monitor or wearable device that is used for capturing outcomes (e.g. diabetes) and/or specialist nursing teams supporting an individual, then that information would be useful to supply.

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[19] In the research study it was clearly communicated that participants could take a break at any time or withdraw from the exercise completely if they wanted to. Referrals to national helplines were also sent out to all participants. Some participants who were finding it challenging, changed to interview only rather than finishing the diary study.

However, there were also a number of concerns related to data sharing which included:

- **A lack of evidence due to low or irregular contact with health professionals:** Not all people with conditions that fluctuate or change over time regularly contact health professionals when symptoms are at their worst or attend regular check-ups. This might depend on the types of conditions involved, the length of time living with the conditions, and if claimants know how to manage fluctuations or changes themselves.

> "If you can give permission [for your GP to share health records] that could really help. It would take away stress and anxiety about trying to contact the right people. But my GP doesn't have everything. There are missing records [my doctor doesn't have]."
>
> (Female, 35-44, mobility, dexterity and cognitive conditions, currently receives PIP)

- **Length of time for diagnosis:** Some participants had waited a long time for diagnosis and wondered what implication this would have on any reliance on medical data.
- **Privacy and confidence:** There were privacy worries about sharing health data. There were also some concerns that people would be less open and confident with their health professional for fear it may impact their benefits.
- **Interpretation of evidence:** There were concerns that DWP might not have the people in place with the skills needed to interpret medical evidence properly.

> "Assume this is a formal diagnosis – but what about people caught in the middle and it is taking a long while to be diagnosed. Is there a way of accounting for it if there is a lack of evidence." (Interview)
>
> (Female,18 to 24, Cognitive and mental health conditions, experience of Access to Work)

5.4.3 Specialist assessors

The concept of being assessed by assessors who were specialists in some conditions was also discussed in some of the interviews.

Some participants welcomed the prospect of specialist assessors as it was felt to promote a better understanding of conditions and impacts during the assessment. It was also reported that seeing someone in the assessment with a good baseline understanding could help open-up the conversation more easily.

However, there were also some concerns raised in relation to this concept:

- **Administration, logistics and timing:** Participants questioned if being matched to specialist assessors would have an impact on appointment setting and lead to possible delays in the process.

- **Ensuring the right assessor is matched to an applicant:** Participants asked about how a specialist would be singled out if there were co-occurring conditions (the majority of participants in the research did indeed have multiple conditions).

Reassurance would be needed that the specialist assessor was qualified and up-to-date in terms of their understanding of symptoms and conditions of the conditions of relevance for the claimant.

> "That's great if they are do it [have specialist assessors]. Very difficult to manage, I suppose auto immune diseases… I have an MS nurse and presumably other long-term conditions have the same. As long as they are specialists, and they have credentials and those credentials can be checked."
>
> (Female, 55-64, long-term health condition, experience of PIP)

5.5 Key takeaways for DWP

1. Fluctuating conditions can make DWP application and assessment processes more challenging in a range of ways that are related to experiencing changes in symptoms across time, and the uncertainly that creates.

2. Some of the difficulties shared by the research participants with fluctuating conditions are likely to be consistent to the experiences of any applicants, with stable or fluctuating conditions. For example, improvements in the accessibility and usability of formats throughout the process. We have not focussed on those here.

3. Some challenges noted in the research are amplified for people whose conditions vary across time. Amplified impacts include the length and complexity of the application process. Although this has consequences for all applicants, future uncertainty of functional, cognitive or emotional capability makes a longer process hold greater risk and difficulty to plan and complete. This is particularly true when there the process has time restrictions for completion.

4. There are DWP options for granting time extensions today. It may be helpful to be more widely publicise who can apply for these and how.

5. Some challenges noted are specific to people with fluctuating conditions. Improvements could be made to designing questions and approaches that are more tailored to effectively communicating changing access needs and varying daily living challenges. The framework outlined - including understanding underlying conditions (including predictability and manageability of the condition/s), triggers, personal management approaches, outcomes and impacts - could help continue to progress this.

6. When thinking about impacts on daily living activities it would be helpful to provide a broader range of options that recognise times when someone can do something

but it will generate an undesirable future consequence or trade off. Asking about what can and can't be done on different days over a useful reference period is a good starting point. Providing space for descriptions of consequences of undertaking activities would also be helpful.

7. Guidance in writing, or support in person from DWP specialists or external agencies would be appreciated by claimants to help them confidently complete the application and assessment processes. This could help address some of the fears people with fluctuating conditions have about being misunderstood.

8. Time-bound activities such as in person or virtual assessments could offer an option to reschedule if a claimant experiences a flare up of symptoms that renders them unable to get there or present themselves equitably.

9. The three initiatives that emerged as recommendations from the White Paper[20] were all quite positively received, with provisos as to how they are implemented. These included generating a Health Impact Record capturing changes over time, gathering evidence directly from a GP or the NHS, or having specialist assessors with experience better matched to the needs of the applicant. All would be worth additional investigation and discovery.

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[20] DWP Policy Paper "Transforming Support: The Health and Disability White Paper", March 2023

Discussion and implications

Currently the application and assessment process at DWP presents a range of challenges for people living with fluctuating conditions that are not the same for those with more stable disabilities and conditions.

Understanding fluctuating conditions is complex. There was extensive diversity across the participants involved in this research in terms of personal challenges, characteristics and contexts of their experiences living with conditions that vary to differing degrees of predictability and manageability over time. They also had differing experiences with DWP in terms of benefits applied for and received since the onset of their condition/s.

Through this research we identified a framework for better understanding the varying challenges of living with a fluctuating condition/s that generates cycles of impacts on daily activities. Some impacts are immediate, and others can be implications of undertaking an activity now that limits another activity in the future.

The framework includes,

- **Underlying condition/s** including how predictable and manageable they are.
- **Triggers** that may be known or unknown which can initiate a worsening of symptoms.
- **Management** approaches an individual may know and be able to adopt in their lives which are helpful for them to prevent or manage flare ups
- **Outcomes** of symptom changes in terms of fluctuating physical, emotional, or cognitive capabilities
- **Impacts** of the fluctuations on what a person can undertake in their daily life.

From the research we have outlined four areas for further investigation by DWP where challenges that are more specific to fluctuating conditions could be practically addressed. These include,

- Improving the questions asked, aligning them to the framework noted above
- Increasing the flexibility in the process (time and range of formats)
- Upskilling staff involved in assessments and applications
- Providing additional support and guidance to claimants

These are in addition to the three suggestions from the “Transforming Support: The Health and Disability White Paper” that we were asked to specifically explore with participants.

Each of the White Paper initiatives received positive feedback. Participants also had concerns about each. Their extent of overall positive impact would depend significantly on the way in which they were implemented.

Whatever options are progressed as a result of these insights, as DWP develop the ideas into solutions, we would recommend ongoing engagement with individuals who have a diverse range of lived experiences of fluctuating conditions. They can help make sure that the translation from idea to action is well suited to the challenges being addressed.

Appendix

Appendix A: Methodology

Stage one: Online survey

The online survey was the first phase of research, and it was designed to give a breadth of understanding, about how a condition might fluctuate (frequency and duration of changes), what might trigger these changes, and the impacts of these changes. Table 1 gives details of the breakdown of participants in terms of the spread across broad categories of disability and conditions. The survey achieved high enough base sizes for sub analysis.

Table 1: Base sizes by category of condition

Condition Category	Number of participants with conditions that change in each broad category
Sensory conditions: Including D/deaf, hearing loss, blind, and partially sighted	76
Mobility/dexterity: Including wheelchair users, restricted ambulation, balance challenges, lower limb loss, weakness, dexterity challenges (tremor, missing upper limb or hand, low grip strength or control) and musculoskeletal conditions (for example back or neck and shoulder)	166
Cognitive: Memory challenges (for example, due to dementia or acquired brain injury), specific learning difficulties (such as Dyslexia, Dyspraxia or Dyscalculia), generalised learning disabilities and other 'neurodiverse' conditions, for example autism or ADHD.	77
Mental health/Other long-term health condition: Anxiety or depression and other mental health conditions, other long-term health conditions for example diabetes, multiple sclerosis, heart conditions, epilepsy, inflammatory bowel disease and chronic pain or chronic fatigue conditions	176

In terms of sampling, Open Inclusion[21] (Open) is an inclusive research agency with a community of over 750 people in the UK who identify as disabled or have additional access needs. The community represents people who sense, think and move differently. The entire community was sent an online link for the survey and, in addition, community members were asked to reach out to family, friends and peers with any disability, condition or access needs that changed over time. Open also sent the survey link to relevant disability organisations to increase the number of participants.

Respondents were eligible for the survey if they were aged 18 or older and living in England or Wales and they observed that the severity of their symptoms or

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[21] openinclusion.com

conditions changed over time. They needed to observe at least one significant impact in everyday activities due to these changes.

Fieldwork ran from mid-January to mid-February 2023 and a total of 297 participants, who identified that their conditions changed or fluctuated over time, completed the survey.

Besides demographics, the survey covered the following aspects of living with conditions that have symptoms that change over time:

- Experiences of changes over time.
- Impact of fluctuating or changing symptoms.
- Support for changing symptoms or conditions.

All participants were offered the option to do the survey in an alternative word format. It is important to note that participation in this survey was self-selecting and, whilst the findings provide a wealth of information to help the understanding of fluctuating conditions, these conditions are often specific to an individual and the results cannot be taken as representing the whole disabled community with fluctuating conditions.

Stage two: Diary study

In terms of sampling, the diary study participants were selected from the online survey participants. They were targeted so that the diary study would include a spread of participants by age, gender, type of conditions, regularity/duration and reported impact of fluctuations or changes in condition.

A total of 46 participants completed the diary study, which was a four-week exercise (between 14 March and 13 April 2023). A dedicated online diary software tool called Dscout was used by most participants. To accommodate other preferences related to accessibility requirements, five participants used Word questionnaires and one used WhatsApp to respond.

Participant responses on the Dscout platform were mostly made via short video clips of one to two minutes. Participants could also provide text or voice only entries depending on their communication preferences. The diary study was made up of the following tasks:

- Task 1 captured a baseline description of physical and mental health and how symptoms were on day one of the study.
- Task 2 was a continuous call out for individual entries as and when symptoms significantly changed over the four-week period. Participants could make as few or as many entries as needed to reflect changes in how they were feeling. Each diary entry included a description and follow up information relating to scoring of physical and mental health and related impacts.
- Task 3 involved weekly round ups.

- Task 4 was a final review of the exercise.

Participants provided a wide range of insights. We thank them for their time and willingness to do so. In total there were 804 individual entries (online, Word or WhatsApp), 544 of which were related to Task 2: daily entries reflecting changes in symptoms.

The diary charted how participants felt from their first entry through to their final entry. Participants varied in terms of their baseline regarding physical and mental health at the outset of the diary task. They were asked to score themselves between a 1 and 5, with 1 being not good at all and 5 being very good:

- Physical health: Just over a third (35%) rated themselves at the lower end of the scale, as a 1 (not good at all) or 2 out of 5 at the outset of the diary in terms of physical health. Another third (33%) placed themselves on the mid-point of the scale (3 out of 5) and three in ten (30%) at the upper end of scale as a 4 or 5 (very good) out of 5.
- Mental health: Just over one in ten (12%) rated themselves at the lower end of the scale, as a 1 (not good at all) or 2 out of 5. Three in ten (30%) placed themselves on the mid-point of the scale (3 out of 5) and almost half (48%) at the upper end of scale as a 4 or 5 (very good) out of 5.

Stage three: In-depth interviews (online)

The third stage of research entailed in-depth interviews with those selected for the diary study. 49 participants completed this stage of the research. Three participants who were unable to complete the diary study participated in the interview stage.

Interviews were conducted by researchers from Open Inclusion and Basis Social between 11 April and 28 April 2023. Interviews lasted up to 60 minutes, building in flexibility for longer or shorter interviews depending on individual needs. Interviews were carried out online via Microsoft Teams.

Topic areas for the depth interviews included:

- The ability to expand on areas that participants felt they could not discuss in the diary study (if they felt they could not accurately represent themselves).
- Experiences of the application and assessment process for DWP.
- Possible improvements to the process and questions asked during the process.
- Getting feedback on the ideas in the White Paper (the Health Impact Record, an option for DWP to access information digitally directly from GPs or other sources to support a claim, and also the option of assessors who specialise in conditions they assess).

The research team employed framework analysis to analyse and synthesise the insights. This involved developing a thematic framework or coding scheme based on the research objectives and evolved lines of questioning, and the data itself. Through analysis and interpretation, patterns of responses and relationships were identified, leading to well-supported conclusions. This was supplemented by regular brainstorms across members of the field team in Open Inclusion and Basis Social to identify and sense-check conclusions.

Appendix B: Detailed sample breakdown

Table 1: Breakdown of participants who completed the survey

Survey participants = 297	No. of participants
Type of disability or access needs (many participants had two or more co-occurring needs)	
D/deaf	12
Hearing loss	41
Blind	48
Partially sighted	27
Mobility – wheelchair user	75
Mobility – restricted ambulation, balance challenges, lower limb loss, weakness	118
Dexterity – tremor, missing upper limb or hand, low grip strength or control	78
Musculoskeletal – for example back or neck and shoulder	75
Memory challenges (for example, due to dementia or acquired brain injury)	27
Specific learning difficulty (such as Dyslexia, Dyspraxia or Dyscalculia)	39
Generalised learning disability	9
Other 'neurodiverse' conditions for example autism or ADHD	50
Anxiety or depression	104
Other mental health condition	26
Long-term health condition, for example diabetes, multiple sclerosis, heart conditions, epilepsy, inflammatory bowel disease	136
Chronic pain or chronic fatigue	104
Gender	
Female	177
Male	106
Other non binary	9
Prefer not to say	5
Age	
18 – 24	12
25 – 34	59
35 – 44	53

Survey participants = 297	No. of participants
45 – 54	63
55 – 64	58
65 plus	47
I prefer not to say	5
Working status	
Working full/part time/self-employed	136
Full or part-time education	12
Not working/voluntary/retired/in education	139
Prefer not to say	10
Benefits status	
In receipt of benefits listed	229
Not in receipt of benefits listed	57
Prefer not to say	11
Benefits in receipt of (5 or more mentions)	
Personal Independence Payment (PIP)	155
Employment and Support Allowance (ESA)	61
Disability Living Allowance (DLA)	50
Universal Credit (UC)	33
Carer’s Allowance	9
Attendance Allowance	6
Incapacity Benefit	5
Severe Disablement Allowance	5
Any other disability related benefit or payment	10

Table 2: Breakdown of participants in the diary study

Diary study participants	No. of participants
Broad category of disability or access need (Note: a majority will fall into more than category)	
Sensory	12
Mobility/dexterity	31
Cognitive	21
Long-term or mental health conditions	36
Gender	
Female	25
Male	17
Other non binary	4
Age	
18 – 34	13
35 – 54	16
55 plus	17
Working status	
Working full/part time/self-employed	21
Full or part-time education	2
Not working/voluntary/retired/in education	22
Prefer not to say	1
Benefits status	
In receipt of benefits listed	36
Not in receipt of benefits listed	8
Prefer not to say	2

Table 3: No. of participants with fluctuating conditions in broad disability categories

Broad category of disability or access need (Note: a majority fall into more than one category)	No. of participants (total)	No. of participants confirming conditions that fluctuate in this category
Sensory	111	76
Mobility/dexterity	171	166
Cognitive	97	77
Long-term or mental health conditions	210	176

Appendix C: Living with and managing fluctuating conditions

Appendix C provides additional detail to support Section 3.3 in the main document.

Fluctuating conditions are difficult to live with relative to more stable underlying conditions of equivalent severity due to the uncertainty and complexity of managing symptom changes.

Changing symptoms means being able to engage in activities one day and not another or having to ask for support one day and not another. It means not knowing what may be possible tomorrow or next week. The disruption caused by changing symptoms, and the flexibility needed for support and adjustments, is often hard to cope with or describe.

Living with a fluctuating condition

Variability in frequency and duration of changes

A high proportion of participants noted no consistent pattern to the frequency of their symptom changes (24% - 35% by condition type).

Of those who did note perceptible patterns to their symptom changes, daily or weekly frequency was the most common across all condition categories (33% - 49% by condition type).

There were some specific condition category patterns also.

- **Sensory conditions**: A quarter (24%) noted no pattern and just under a half (46%) noted daily or weekly variations. The qualitative analysis found that for sensory disabilities some differences may exist between more mild symptoms and more significant functional changes.

  > “It varies so much. In my life the fluctuations feel longer and based around life events rather than my condition, with milder symptoms changing day by day if I stare at a screen too much etc.”
  >
  > (In-depth Interview, female 45-54, sight loss)

- **Mobility/dexterity conditions:** Those with mobility or dexterity needs were relatively evenly spread between no pattern (30%), daily or weekly frequency (36%) and less regularly than weekly changes (29%). Through the diary and in-depth interviews we heard of the relevance of symptom seasonality for some participants with mobility and dexterity conditions.

  > “My condition is affected by hot and cold and I have a lot of flare ups in the winter so might not get PIP in the summer but would in the winter.”
  >
  > (Depth Interview, non-binary, 18-24, mobility and long-term health conditions)

- **Cognitive conditions:** Over a third (35%) noticed no discernible pattern in their symptom frequency and almost half (49%) noted daily or weekly patterns. Less than one in seven (14%) noted longer patterns of fortnightly or more. The qualitative analysis described ongoing regular fluctuations disrupting life.

> “The unexpected happens all the time. We don't have the luxury of cognitive fluidity, it's in the nature of my condition. Every day throws up new obstacles that "normal" people dodge without having to calculate consciously, but for us we have to work round them and it fizzes our thinking skills, our skills to adapt”
>
> (Diary, male, 45-55, cognitive conditions)

- **Long-term health and mental health conditions:** Participants noted a very balanced spread of frequency between no discernible pattern (33%), a shorter cadence pattern of weekly or more often (33%) and a longer pattern of fortnightly or more (33%). Through the qualitative research we also heard that some conditions are much longer term in variations.

> “A year would be a good duration to understand my condition. The depression has a longer factor, takes longer to come out of it, anxiety and OCD have more present awareness of, eating disorder between the two and three months.”
>
> (Depth interview, female, 25-34, long-term health and mental health conditions)

Duration: how long

Many participants have very little sense of how long changes in symptoms caused by a flare up will persist. Depending on the condition type, between a third and nearly half of all participants noted no observable pattern to how long changes lasted (36% to 47%).

Where people did notice a discernible pattern of duration, the changes were more likely to last for hours or days rather than weeks or months.

The most notable differences across condition communities in patterns of duration were:

- **Sensory conditions:** Those with sensory needs on average had slightly more identifiable patterns of symptom duration. 36% noted no identifiable pattern. For those with identifiable patterns a quarter (25%) noted very short-lasting changes: lasting minutes or hours. This was higher than any of the other condition communities.
- **Cognitive conditions:** As per frequency, those with cognitive conditions had the highest level of no identifiable pattern for duration of a flare up (47%)
- **Long term conditions and mental health conditions:** This grouping of conditions had a slightly higher proportion of participants who noted longer

duration impacts (19% reported weeks, months or longer) relative to other conditions. This was still much less than those in the same condition group who noted short duration changes (39%) or no discernible pattern (40%).

Table 1: Frequency which significant changes occurred

Frequency which significant changes occurred	Sensory	Mobility/ dexterity	Cognitive	Long-term and mental health conditions
Participants by category	76	166	71	176
Daily	25%	22%	23%	14%
Weekly	21%	14%	26%	19%
Twice a month	4%	9%	8%	10%
Monthly	11%	9%	1%	8%
Once every few months	5%	8%	4%	9%
Twice a year or less often	3%	1%	0%	4%
Other	7%	2%	1%	2%
No pattern/ it varies	24%	30%	35%	33%

Q How often do you typically experience these significant changes? We appreciate that there may be no pattern. Please give us your best estimate based on what has happened in the past
This is the tabular form of Figure 3.1

Base: All participants noting changes in reference to condition type: Sensory (76), mobility/ dexterity (166), cognitive (71), long-term conditions and mental health conditions (176)

Table 2: Duration: Length of time significant changes usually lasted

Duration: Length of time significant changes usually lasted	Sensory	Mobility/ dexterity	Cognitive	Long-term and mental health conditions
Participants by category	76	166	71	176
Minutes/Hours	25%	17%	19%	15%
Days	16%	21%	22%	24%
Weeks	9%	9%	4%	13%
Months	4%	4%	4%	3%
Other (specify)	3%	3%	1%	3%
There is no pattern/ it varies	36%	40%	47%	40%
Don’t know/not stated	8%	5%	3%	2%

Q: How long do these significant changes usually last for? Please include the time that symptoms are more severe and the recovery time you may need.
This is the tabular form of Figure 3.2

Base: All participants noting changes in reference to condition type: Sensory (76), mobility /dexterity (166), cognitive (71), long-term conditions and mental health conditions (176)

Appendix D: Triggers: Additional data tables and charts

Appendix D provides further details to support the information shared in Section 4. The areas where additional details are shared are triggers, management of conditions and impact of living with a fluctuating condition.

Triggers

Table 1. Specific triggers (This is the tabular form of Figure 4.2)

Specific triggers (mentioned by +5% of participants)	Sensory	Mobility/ dexterity	Cognitive	Long-term and mental health conditions
Participants by category	76	166	71	176
Diet	9%	12%	21%	24%
Exercise (too much/too little)	11%	61%	29%	47%
Weather (heat, cold, wet etc.)	46%	78%	43%	55%
High stress or anxiety	50%	64%	90%	80%
Sleep (too much/too little)	49%	51%	77%	60%
Allergies	13%	7%	13%	10%
Virus or infections	28%	48%	22%	35%
Don't know/No specific triggers	21%	13%	9%	15%

Source: Online survey (Base: all participants 297)

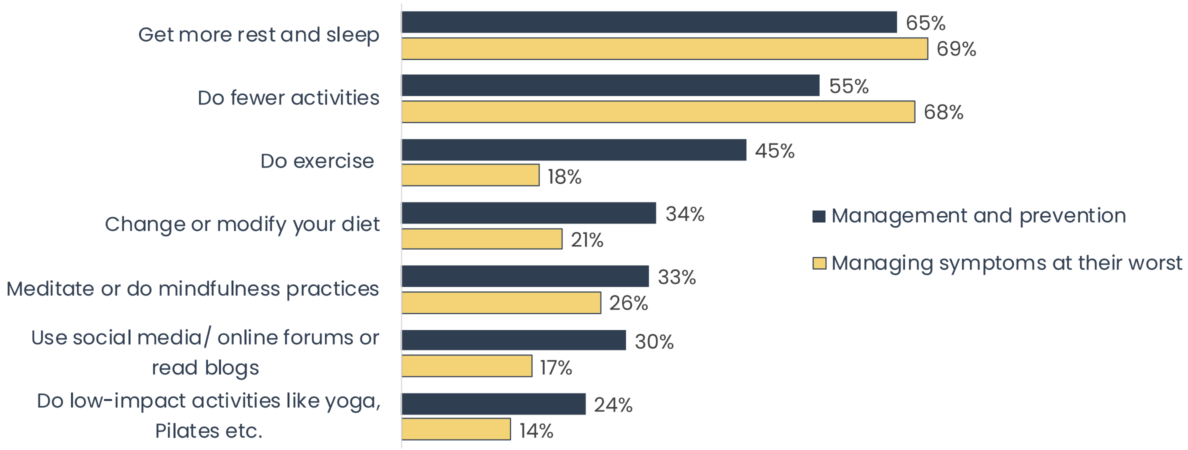
Managing Fluctuating Conditions

Through the research we learned about three major ways that people proactively or in response to a flare up manage their underlying conditions. These were self-care techniques, taking medications or going to therapy and getting advice and support from health and non-health professionals.

1. Self-care techniques

In the survey participants were asked to consider what management tools they used in relation to two contexts; ongoing management and prevention of symptoms getting worse and response to managing symptoms when they were at their worst. This was reinforced through findings from the diary study and interviews.

Figure 1. Self-management approaches adopted to prevent and manage flare ups



Q: Do you personally do anything to try and manage your symptoms or prevent them from getting worse? and Q: When the symptoms you told us about are most severe, do you personally do anything to manage them in those times?

Base: all survey participant (297). ‘Other’, 'Don’t know’ are not shown.

This is the tabular form of Figure 1

Managing symptoms – self-care techniques	Managing symptoms at their worst	Management and prevention
Get more rest and sleep	69%	65%
Do fewer activities	68%	55%
Meditate or do mindfulness practices	26%	33%
Change or modify your diet	21%	34%
Do exercise	18%	45%
Use social media/ online forums or read blogs	17%	30%
Do low-impact activities like yoga, Pilates etc.	14%	24%

Source: Online survey (Base: all participants 297) Self-care categorised responses.
‘Other’ and ‘don’t know’ are not shown (mentions were under 5% in each case)

- **Rest and sleep.** Rest was often the only way that people could cope with the flare up or episode and was hugely important for recovery. While rest was seen as an integral and important part of management it also came at a cost of having to miss out or scale back on day-to-day plans and activities. It also was used in conjunction with other approaches such as medication, diet and other self-care.

> “Pain killers, a bath and bed rest normally helps.”
>
> (Diary, male, 45-54, long-term health conditions)

> "Rest, plain foods, painkillers and spoke to GP to see if [there is] any further help I can get from the consultant"
>
> (Diary, non binary, 25-34, long-term and mental health conditions)

- **Moderating activities** was also an important self-care technique both for ongoing management and when symptoms are at their worst.

> "Depending on how I feel and how my body feels on the day, depends on what I do that day. I try not to make a massive list of what needs doing as I become overwhelmed and go into a freeze and don't do anything."
>
> (Survey, female, 18 to 24, long-term health and mental health conditions)
>
> "I have not been able to do as much as I have needed to due to a current flare up of symptoms and generally struggling with all my conditions…I have not been able to get things done like housework and I am trying to preserve energy so amending tasks I need to do such as making easier meals that require less energy. [I] have also had to rest more."
>
> (Depth interview, female 25-34, Mobility and Cognitive conditions)

- **Exercise** was particularly important for prevention but not so important in a flare up.

> "Everything, pain and mobility is just ongoing. The weather has been warmer which does help and I've tried to start going out on daily walks. However, when I come home I am very fatigued. I do want, and need to keep the exercise up going forward or I will lose the mobility that I've got.
>
> (Diary, female, 55-64, long-term health conditions)

- **Diet, meditation and mindfulness** were all used by approximately a third of participants in terms of management and prevention and by fewer as a management practice when symptoms were at their worst.

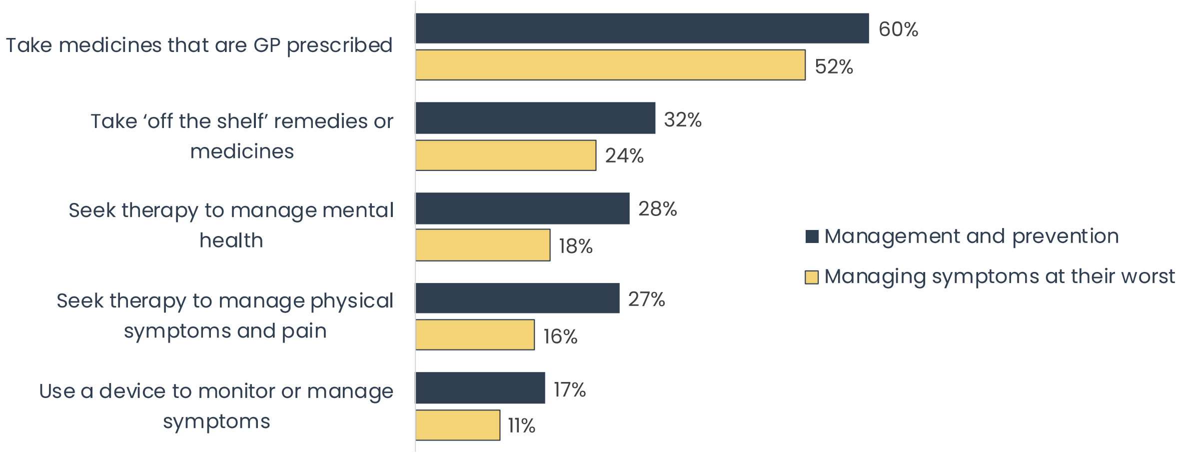
> "Watching my diet. Resting when I need to. Good sleeping pattern. Hobbies. Reflexology. Being kind to myself. Keeping medical appointments. Being sensible"
>
> (Diary, female, 65-74, long-term health conditions)

- **Low impact activities and use of social media networks** were approaches adopted by a quarter or more of the participants. Again, these were more used in preventative management than once symptoms were at their worst.

2. Medical and therapeutic management techniques

In addition to self-management techniques, through the survey as well as in the diary study and interviews we heard that people engaged in a variety of medical and therapeutic support to manage symptoms.

Figure 2. Medical and health industry approaches adopted to prevent and manage flare ups



Q: Do you personally do anything to try and manage your symptoms or prevent them from getting worse? and Q: When the symptoms you told us about are most severe, do you personally do anything to manage them in those times?

Base: all survey participant (297). 'Other', 'Don't know' are not shown

Table 2. Managing symptoms – medical and health industry techniques

The tabular form of Figure 2.

Managing symptoms – medical and health industry techniques	Managing symptoms at their worst	Management and prevention
Take medicines that are GP prescribed	52%	60%
Take 'off the shelf' remedies or medicines	24%	32%
Seek therapy to manage mental health	18%	28%
Seek therapy to manage physical symptoms and pain	16%	27%
Use a device to monitor or manage symptoms	11%	17%

Source: Online survey (Base: all participants 297) Medical categorised responses
Other, don't know are not shown (mentions were under 5% in each case)

From this we can see that,

- **Prescribed medications** were the most common route to manage symptoms both preventatively and in response to the symptoms at their worst.

> "Continue with new antidepressants. I am seeing my neurologist on Friday for yearly meeting. I am awaiting an appointment to discuss my urinary issues."
> (Diary, female, 45-54, long-term health and mental health conditions)

- **Off the shelf remedies or medicines** were used by a third of participants to manage and prevent symptoms. This drops to a quarter of participants when symptoms were at their worst.

> "I will have to take pain relief and anti inflammatory medication and rest. I do also tape my fingers together to help with the pain."
>
> (Diary, female, 65-74, mobility and long-term health condition)

> "Mentally I'm in a bit of a better place. I've started taking St John's Wort rather than the antidepressants recently and I do feel better. Whether that's down to the supplement or just me taking control of things I don't know but really does that matter if it works?"
>
> (Diary, female, 55-64, long-term health condition)

- **Therapy** was also used for mental health by 28% for ongoing management and 18% when symptoms were at their worst. Therapy was used for physical symptoms and pain by very similar proportions of participants (27% ongoing and 16% for when symptoms were at their worst)
- **Using a device to monitor or manage symptoms** was used by 15% of participants which fell to just over 10% when symptoms were at their worst.

3. Engaging with health and non-health professionals

In the survey participants recorded their use of professionals to help support their conditions. This included doctors and other health professionals such as therapists, and also other professionals such as support organisations and government organisations.

In terms of ongoing management and prevention of fluctuations, the GP/Doctor was most commonly mentioned:

- GP/Doctor (65%)
- Social media/online forums and blogs (34%)
- Physiotherapist/personal trainer (28%)
- Pharmacists (28%)
- Local charities and Non-Government Organisations (25%)
- Therapist/psychiatrist (24%)
- National charities and Non-Governmental Organisations (20%).

Fewer participants used the health and non-health professionals listed above when symptoms were at their worst. Importantly, over a third (36%) said that they did not get any support at these times compared to 12% in relation to ongoing management and prevention. This illustrates the point made earlier in the report about individuals having a reduced bandwidth when a fluctuation is occurring. It was also corroborated by entries in the diary study, where bed rest was sometimes the only solution to managing symptoms when they were at their worst.

> “I am at home in bed and in agony. Today is a really bad pain day and [I have] almost zero mobility.”
>
> (Diary, female, 65-74, mobility and long-term health conditions)

In summary, people with fluctuating conditions use a very wide array of approaches to avoid and minimise the impacts of flare ups. The range and extent to which they can adopt management approaches declines when their symptoms are at their worst.

Outcomes

Table 3: Themes related to the outcomes of fluctuating conditions

Thematically analysed from an open question.

Theme	Number of mentions
Coping with changing/managing activities: Changing activities/unable to do abilities/narrowing what can be done/prioritising/modifying/taking longer	143
Detailed planning: Planning/plan to extreme/detailed/plan B/increase planning/cautious planning	109
Difficulty planning: Avoiding making plans/hard to plan/cannot plan far in advance	82
Relationships; impacts on other people	47
Managing emotional responses and self worth; stress, anxiety, demotivation, loss of confidence, low mood	38
Loss of independence, asking for help, seeking more help	27
Total mentions (multiple themes possible)	**446**

Q: In your own words, please tell us how living with your changing symptoms or condition(s) makes you feel about planning and undertaking daily activities

Source: Online survey (Base: all participants 297)

Impact of living with a fluctuating condition.

Fluctuating capabilities commonly disrupt short term plans and the ability to undertake activities and expectations at home, work or education, and in an individual's personal life.

In addition to impacting today's activities, they have the potential to also generate future limitations. These are secondary or 'knock-on' effects that result from the chosen or required level of activities undertaken today. Individuals can exceed their limits in ways that leave significant deficits in resources such as energy, or which trigger new flare ups in symptoms that create future impacts.

Evidencing wide-ranging impacts

In the survey a majority of participants reported that they had either not been able to do some or all of the activities within the categories defined, or that achieving them had been possible but harder to complete in the past two years as a result of having a condition that fluctuates.

Leisure activities

In the survey, 89% noted that they had experienced an impact or inability to undertake leisure activities in the past two years.

Over half, (57%) could not do some or all of their activities. This was the highest complete inability to undertake activities across all seven categories. A further 32% found it harder to undertake activities but they could do them. Only 9% had no impact on leisure activities.

From the individual diary entries, 234 of the entries observed that they experienced a change which had an impact on leisure activities.

Types of leisure-related impacts mentioned by multiple participants included:

- Exhaustion or pain symptoms after being away for a few days
- Challenges being on holiday if a change or fluctuation occurs
- Enjoying or being unable to do some limited exercise such as a walk or swim
- Taking a trip if symptoms will allow (to the shops or cinema)
- Being unable to do the gardening or enjoy the garden
- Having the break over the Easter led to some feeling relieved from symptoms due to the break and then feeling worse

A positive experience of leisure activities can generate an uplift in mood. Participants valued this even when the activity may be somewhat restricted due to the symptoms of their fluctuating conditions, and the potential of triggering a negative fluctuation as a result of the planned activity.

> “Better day today as I had a reasonable night's sleep. Went out for a little walk, slightly better and the sun was out. Hip and back/shoulders painful and got tired quickly. Completely zoned out for 15 mins when I got home as so fatigued. Better than yesterday and hopefully tomorrow will see more improvement.”
>
> (Diary, female, 55 to 64, long-term conditions)

Social activities

In the survey 88% noted that they had experienced an impact or inability to undertake social activities in the past two years.

Over half, (56%) could not do some or all of their activities. A further 32% found it harder to undertake activities but they could do them. 12% had no impact on social activities.

From the individual diary entries, 226 of the entries observed that they experienced a change which had an impact on leisure activities.

Types of social impacts mentioned by multiple participants included:

- Cancelling or postponing plans due to flare ups starting and wanting to rest
- Missing special occasions
- Having to rearrange plans after a flare up
- Worrying about long term impacts on friendships and relationships

Frustrations at missing social engagements was a very regular challenge for participants. Many had concerns about the implications this had on friendships and personal sense of self-worth.

> "I am feeling low, fed up and generally hopeless. I am so tired but unable to sleep due to cramping in my abdomen. … I am supposed to be meeting friends tomorrow and I am not sure if I will manage getting there. It’s another thing I have been unable to attend and I don't think people understand. It’s just frustrating with how my life has changed and makes me feel like a failure."
>
> (Diary, non-binary, 25-34, cognitive, long-term health and mental health conditions)

Special occasions that couldn’t be attended or where they had been negatively impacted by changing conditions were particularly frustrating for participants.

> “I seem to be coming out of this flare up. But my back is bad again so I can't even lie down for too long. Which makes resting difficult. It's my birthday today so have had lots of lovely cards and messages. And one of my daughters is cooking me my favourite dinners. I wish my hands would stop hurting. It's a worrying new symptom.”
>
> (Diary, female, 65-74, long-term health and mental health condition)

Household activities

In the survey exactly the same proportion of participants as we noted in work activities, 91%, noted that they had experienced an impact or inability to undertake household activities in the past two years.

Over half, (54%) could not do some or all of their activities and a further 37% found it harder to undertake activities but they could do them. Only 9% had no impact on household activities.

From the individual diary entries, 258 of the entries observed that they experienced a change which had an impact on household activities.

Types of household impacts mentioned by multiple participants included:

- Difficulty carrying out household activities due to lack of energy, pain or needing to rest
- Shopping for food
- Needing help getting dressed and bathing
- Cooking: difficulty using equipment in the kitchen and some needing to rely on pre-made food or ready cooked meals
- Laundry tasks
- Spending time and enjoying playing with children
- Looking after pets

Many participants noted frustrating restrictions due to their condition/s when undertaking basic home tasks and playing with their children.

> “I was exposed to a different surrounding with a variation in lighting, and this wasn’t my regular setting. After some time I experienced a burning sensation in my eyes. This resulted in me feeling tired and after I returned home, I was unable to complete rudimentary tasks like loading the washing machine and play with my son.”

(Diary, male, 25 to 34, sensory condition)

Personal Travel activities

In the survey 86% noted that they had experienced an impact or inability to undertake travel activities in the past two years.

Over half, (51%) could not do some or all of their activities. A further 35% found it harder to undertake activities but they could do them. 12% had no impact on travel activities.

From the individual diary entries, 138 of the entries observed that they experienced a change which had an impact on travel activities.

Types of travel impacts mentioned by multiple participants included:

- Concerns while planning the trip about the impact of having a flare up or fluctuation just before or while travelling. Fear of having to cancel the trip
- Anxiety about taking everything needed when travelling or once away
- Worries about the impact of travel on symptoms (in planning stage)
- Managing changing symptoms during travel or after it that were triggered as a result of travel
- Safety concerns related to personal travel
- Looking after valuable and personal belongings when travelling

Planning for travel was often difficult for those with fluctuating conditions. It raised additional concerns for participants about how symptoms may influence the experience and needs while away.

> "My concerns are, how my back will be on the journey, the early start, and how my blood sugar levels be and making sure I eat something before I leave home, as I am driving? I know it will be okay, and I will manage it, as it is a journey I have made a number of times."
>
> (Diary, male, 55 to 64, long-term conditions)

The travel itself could trigger a change in conditions as normal self-management routines were not so easy to follow.

> "Today wasn't a typical day as we (my husband and I) were visiting the river in Yorkshire so I've been on a 4 hour round trip, I missed lunch, and by 6pm my muscles were shouting very loudly that they needed food, and I suffered a new symptom; painful muscle cramps/spasms. I also had a way to walk from the car park to the bridge over the river ([I] couldn't have got my wheelchair up the path), and my legs hurt quite a bit on the way back."
>
> (Diary, female, 55 to 64 mobility/dexterity and long-term conditions)

Work activities

In the survey 91% of participants noted that they had experienced an impact or inability to undertake paid or unpaid work activities in the past two years.

Almost half, (49%) could not do some or all of their activities and a further 42% found it harder to undertake activities but they could do them. Only 7% had no impact on their work activities[22].

From the individual diary entries, 189 of the entries observed that they experienced a change which had an impact on work activities.

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[22] The remaining 2% not accounted for were "I don't know" which we removed from the analysis

Types of work-related impacts mentioned by multiple participants included:

- Pain and symptoms caused by travelling for work
- Necessity to pace work to deadlines and stress about mounting deadlines
- Processing information, keeping focussed, finding words and memory challenges
- Difficulty managing meetings
- Typing more difficult when dexterity is worsened
- Recovering from sensory overload due to work
- Impact of working at the computer on the eyes and headaches
- Managing shifts or long days after a flare up or fluctuation
- Anxiety about sleep, considering commitments the next day
- Extra considerations about travel and accessibility if going to a new venue for work or overnight stays

Many participants had concerns about managing work commitments when symptoms were flaring.

> "Two sleepless nights, struggling with breathing, long work hours and no energy to look after myself properly so not eating healthy either. As a result, I'm feeling drained and tired and not sure what to do to feel better because I can't lower my workload at the moment."
>
> (Diary, female, 25 to 34, sensory, mobility and long-term condition)

Managing work travel requirements was difficult for many. This links to varying flexibility people may have to work from home or to minimise offsite work travel.

> "I was at a meeting and my affected knee gave way. This made me trip falling into the stairs at a hotel. It has shaken me. I am anxious about putting weight and trust in my legs. This is a backwards step and is starting to worry me."
>
> (Diary, female, 35 to 44 mobility/dexterity and cognitive)

Anxiety about needing sleep to manage future work commitments can make getting to sleep less likely, especially when sleep has recently been short or interrupted.

> "I have just finished work. Mostly responding to emails. I still have a headache and can't seem to shift it, and I did not sleep well last night. I am going on [an away day] tomorrow. Will need to be up by 5.30 to leave at 6.45. I HAVE to get some sleep tonight to be prepared for the day which will have its own challenges. Going to take my meds early to hopefully enable a positive day."
>
> (Diary, female, 65 to 74, mobility and long-term condition)

Education, training and learning activities

In the survey 83% noted that they had experienced an impact or inability to undertake educational activities in the past two years.

40% could not do some or all of their activities. A further 43% found it harder to undertake activities but they could do them. 15% noted no impact on educational activities.

From the individual diary entries, 108 of the entries observed that they experienced a change which had an impact on educational activities.

Types of educational impacts mentioned by multiple participants included:

- Requesting and agreeing reasonable adjustments, including extended deadlines for essays or more time in exams
- Preparing for and sitting exams or tests can trigger symptoms
- Managing energy and focus to study effectively
- Cancelling going to classes when symptoms flare

Financial activities

In the survey just over a half of the participants, 57%, noted that they had experienced an impact or inability to undertake financial activities in the past two years. Although this is a significant proportion, it was the lowest of all seven activities.

40% could not do some or all of their activities. A further 43% found it harder to undertake activities but they could do them. 15% noted no impact on educational activities.

From the individual diary entries, 86 of the entries observed that they experienced a change which had an impact on educational activities.

Types of financial impacts mentioned by multiple participants included:

- Fear of changing work status and income from redundancy, loss of work
- Lack of income from lack of work or less work than desired

Financial stresses are both a result of having a fluctuating condition/s as well as a trigger for symptoms of them. We heard a number of participants share this dual impact of financial concerns, particularly triggering symptoms of anxiety or depression.

> “Symptoms [were] worse today, had mini melt down due to feeling overwhelmed by ongoing stresses like redundancy and loss of income, as well as property not selling etc.”
>
> (Diary, male, 25 to 34, cognitive condition)