Experiences of Students with Long COVID and Chronic Illness

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Background

The COVID-19 pandemic brought many challenges for higher education students, predominantly through the need for online/blended learning, and subsequent effects on mental health and wellbeing. For students who contracted COVID-19, the impact on learning/university experience may be even greater, as a significant proportion continue to experience symptoms. While most recover from COVID-19 within a few weeks, an estimated 106,000 under 25-year-olds in the UK are experiencing Long COVID, defined as prolonged symptoms of COVID-19 (e.g., fatigue, pain and sensory loss). This often continues for several months after the initial infection (Office for National Statistics, 2021). Estimates vary, but a recent study suggests 7.8% of young adults may experience prolonged COVID symptoms, with 1.2% cases leading to functional limitations (Thompson et al., 2022).

The vast array of Long COVID symptoms mean that students are likely to have highly individualised needs, spanning physical/mental health, emotional and academic support requirements. The profile of symptoms has been likened to that of other Chronic Illnesses, such as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS; Wong and Weitzer, 2021). Similarly, to Long COVID, people with such energy-limiting conditions report a range of fluctuating symptoms that include physical and cognitive fatigue, pain and sensory issues (Hale et al., 2020).

Of the students with a disability in UK universities, 30,110 have a long-standing illness (including unseen disabilities/long-standing health conditions, e.g., cancer, HIV, diabetes, chronic heart disease, or epilepsy; Hubble and Bolton, 2021). While a cannon of research into experiences of students with disability exists, research focussed specifically on students with chronic conditions is limited. However, a recent study by Hamilton et al. (2021) explored this issue in depth, finding themes around identity and perceptions of Chronic Illness, and feelings that these students are under-supported and undervalued members of the university community. Further, Toller et al. (2021) highlighted the frustrations that students with Chronic Illness experience and how the fluctuating nature of their illness sets their support needs apart from those of other students with disabilities. Overall, it is clear more work is needed to support students with Chronic Illnesses, and this support helpfully converges with the needs of students with Long COVID.

Taking these issues as a whole, support provision for students with disability (and subsequently, Chronic Illness) has received governmental focus, with Hubble and Bolton (2021) highlighting that universities need to do more. Students with disability are more likely to drop out of their degree, complete with lower degree results, and are less likely to be in employment after graduation, than non-disabled counterparts. Moreover, in reviewing disability policies, Williams et al. (2017) found only 44% of higher education providers (HEPs) have policies around students experience for disabled students , and 43% have policies for inclusive curriculum design. As such, research into inclusion of students with disability and inclusive practice is vital, and enhances a key strategic priority identified by the University of Warwick (www.warwick.ac.uk/about/strategy/).

Key Aims

This study had three core aims. Firstly, it estimated the proportion of students at the University of Warwick experiencing Long COVID and/or Chronic Illness, in order to determine prevalence such issues (see Hamilton et al., 2021). The second aim was to explore experiences of Warwick students with Chronic Illness and/or Long COVID. Given that previous research (Hamilton et al, 2021) illustrated that appropriate support was difficult to obtain, here, we gathered opinions of Warwick students on accessing available support and navigating the learning and teaching environment. Importantly, we extended previous research findings to explore experiences and opinions of students with Long COVID.

Given that there are some similarities in symptoms experienced by Long COVID and other Chronic Illness, the study focused on whether the experience of students with Chronic Illness can guide support planning for students with Long COVID. For instance, students with Chronic Illnesses, may come to university having had some years of managing their conditions, self-advocating and accessing support, from in-school services. As such they may have more experience of navigating various support services and guidance. The study focused on establishing whether students with Chronic Illnesses do indeed have more experience of managing their conditions, and if so, whether their experiences can help those students newly diagnosed with Long COVID. Information gathered from students in surveys, focus groups and interviews was used to develop self-help resource guides for students with Long COVID or Chronic Illness focused on accessing support for physical, cognitive and mental health needs.

Previous research with students with chronic research revealed that students with Chronic Illness feel their needs are not prioritised by disability support services and that staff lack understanding about the impact of their conditions (Hamilton et al. 2021). Therefore, a third aim was to develop recommendations for the University staff on supporting students with Long COVID and Chronic Illnesses, specifically for personal tutors and disability support staff.

Methods

Participants

Student Survey and Focus Groups/Interviews

Fifty-three students (28 Undergraduate, 13 Postgraduate) from the University of Warwick completed the initial survey. Of these students, 34 (63.15%) were female, 13 (25.53%) were male, 5 (9.43%) were non-binary/ third gender or other and 1 (1.89%) declined to respond. Thirty-Seven students (71.5%) were white British, 7 (13.21%) were Asian or Asian British, 7 (13.21%) were mixed/multiple ethnicity and 2 (3.77%) were Black/African/Caribbean/Black British. The average age was 24.87 (SD=7.85).

Fourteen students (26.42%) reported that they had Long COVID, of which 11 (78.57%) had a formal diagnosis. Thirty-nine (73.59%) reported having a Chronic Illness and 35 (89.74%) were formally diagnosed (see **Error! Reference source not found.** for the frequency of different chronic conditions that participants reported having). Thirty-seven students (71.15%) reported having one chronic condition and 16 (30.19%) reported having 2 conditions.

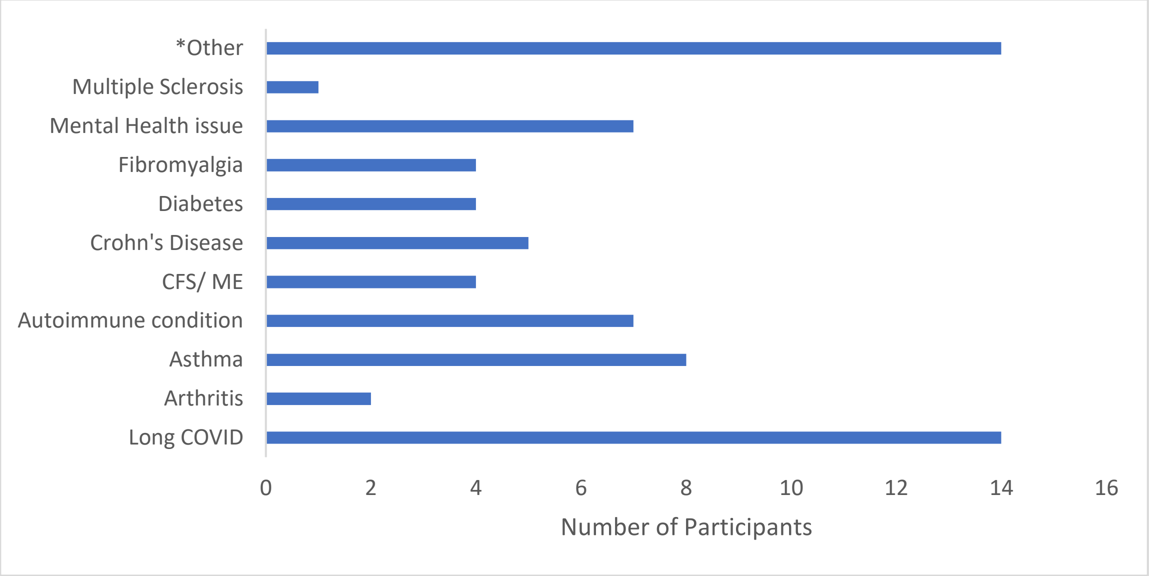

Figure 1. Chronic Illness diagnoses

*Other conditions: Chronic migraine, EBV, Ehlers Danlos Syndrome (4), Postural Orthostatic Tachycardia Syndrome, Endometriosis (2), IBS (2), Systemic lupus erythematosus (SLE), lung and heart issues, MCAS, Ulcerative Colitis

Eight participants also opted to participate in a focus group or one-to-one interview (4 undergraduates, 4 postgraduates). Four of these had Long COVID, and 4 had 1 or more chronic conditions. All students received a £10 Amazon voucher for their time.

Staff survey

Four staff also completed a survey on their experience of supporting students with Long COVID or Chronic Illness. Three were Senior Tutors, and 1 was a Personal Tutor.

Procedure

The initial survey was presented on Qualtrics, and assessed impact of Long COVID and Chronic Illness on different aspects of student experience. The survey was split into 6 main sections; each section included a series of questions requiring participants to rate their experiences, and qualitative questions allowing participants to expand on their views and experiences.

- Section 1: Symptoms, health and wellbeing
- Section 2: Disability support: opinions on university-based and departmental-based support
- Section 3: Reasonable adjustments: opinions of adjustments
- Section 4: Academic impact of condition
- Section 5: Social and family life impact of condition

Following the initial survey, participants were invited to participate in either a focus group or interview. These focused on current support needs, useful resources and advice for other students with Long COVID or Chronic Illness. Staff surveys focused on level of experience in supporting students with Long COVID/Chronic Illness, areas that students common need support and useful techniques or resources.

Results

Section 1: Symptoms, health and wellbeing

This part of the survey focused on the student's symptoms and current health and wellbeing. **Error! Reference source not found.** shows the average severity ratings for common symptoms that students with Long COVID/Chronic Illness experience. Average ratings were similar across students with Long COVID and Chronic Illness for most symptoms, though were slightly higher for memory, attention, and irritability issues for students with Long COVID.

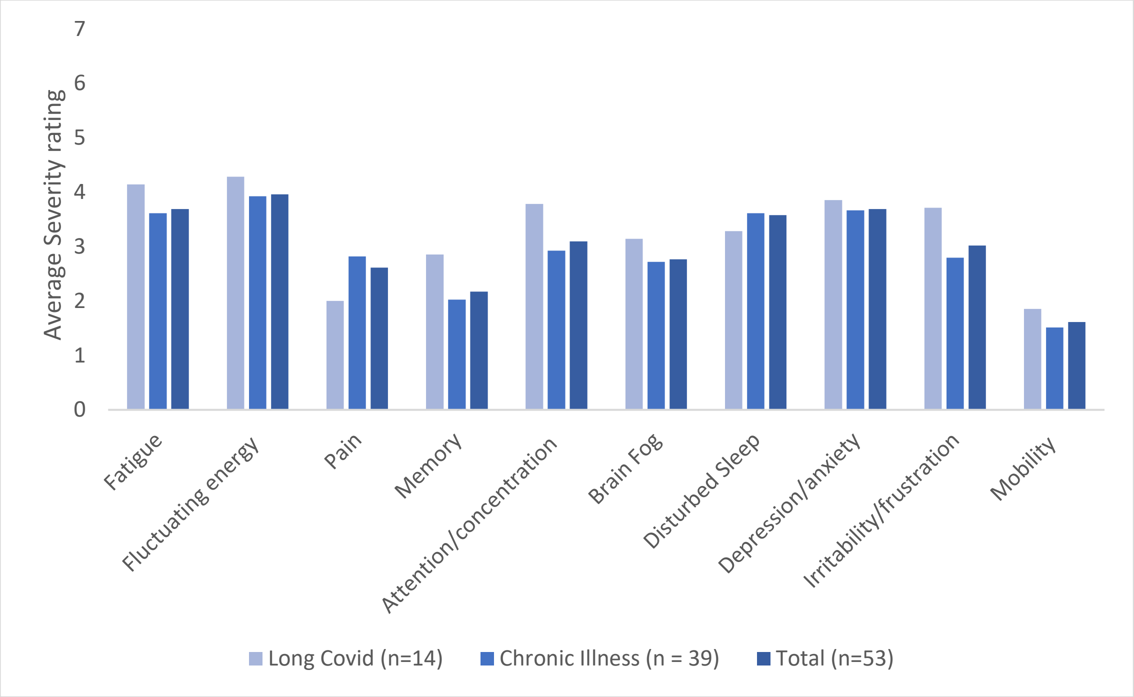

Figure 2: Severity of symptoms for students with Long COVID and Chronic Illness (1 = I do not experience this - 7 = very severe)

All participants experienced some degree of fatigue (60.38% at the "moderate-severe" to "very severe" level), fluctuations in energy (66.04% at the "moderate – severe" to "very severe" level) and sleep issues (54.72% at the "moderate- severe" to "very severe" level). A high percentage also experienced depression or anxiety (50.94% at the "moderate – severe" to "very severe" level).

Memory issues and mobility issues were the least experienced symptom: 24.53% and 39.62% respectively reported not experiencing these symptoms. However, 26.42% and 15.09% experienced these symptoms at the "moderate-severe" to "very severe" level. Figure 3 shows the overall quality of health for students with Long COVID or Chronic Illness. The majority of students rated their current health as either "good" or "fair".

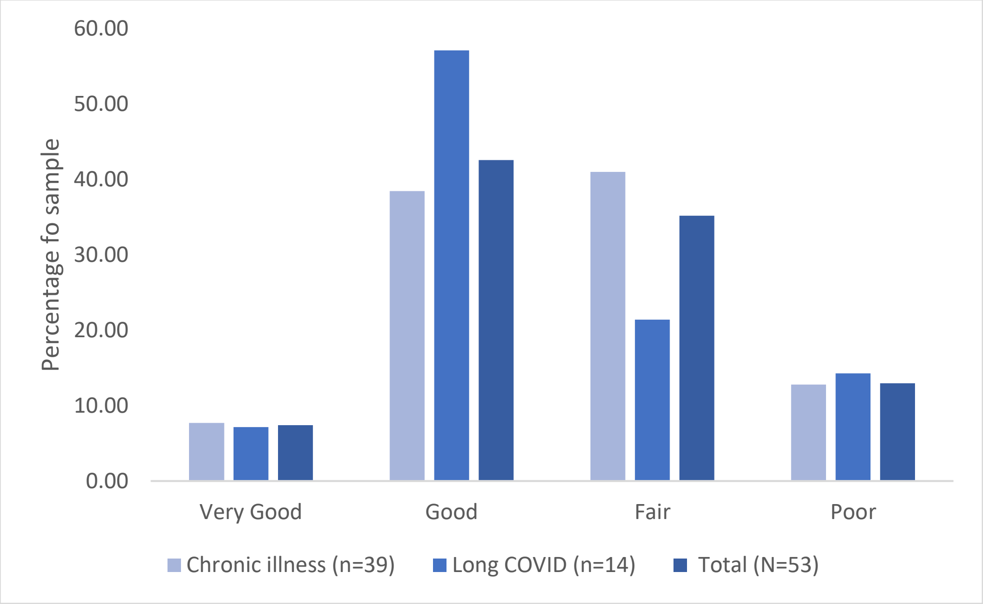

Figure 3: Overall quality of current health

Fewer students with Long COVID reported they overall health to be “good” compared to other students with Chronic Illness (38.46% vs. 57.14% respectively) and more students with Long COVID who reported their health to be “fair” compared to those with Chronic Illness (41.03% vs. 21.43% respectively). Similar proportions of students with Long COVID and chronic illness reported their current health to be “poor”.

Figure 4 shows how many days in the past 30 students’ physical health and mental health was “not good” and how frequently in the same time period health stopped students carrying out normal activities. Along with Figure 3, this illustrated that, while in general students report that their physical health is generally “good” and that this has had a limited impact on their normal activities, mental health was reported as more impacted in this timeframe.

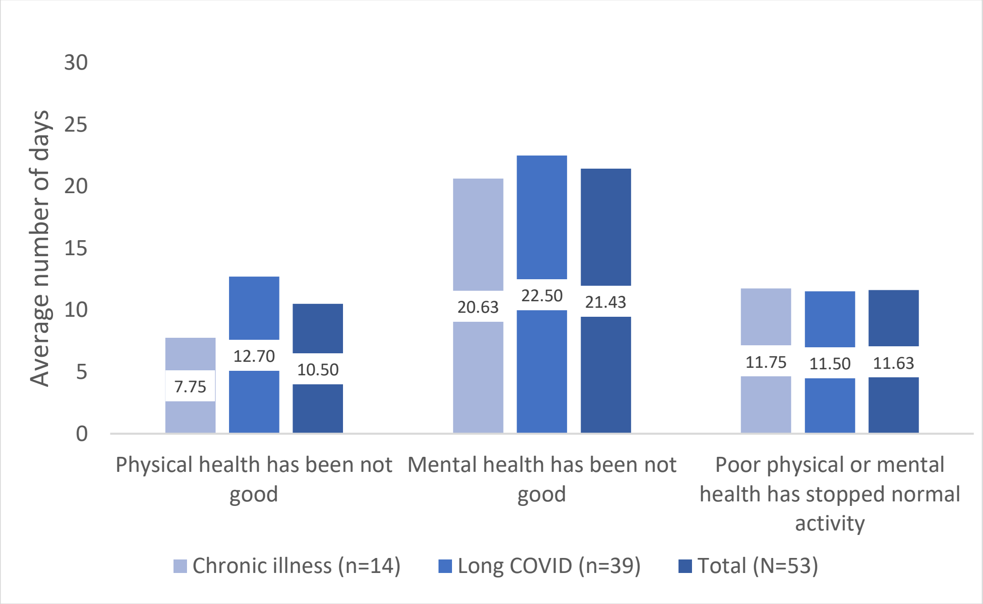

Figure 4: Average number of days in the past 30 that health has not been good

Generally, the physical health of students with Chronic Illness appeared to be better than that of people with Long COVID. Overall, physical health was least impacted in comparison to mental health (overall average of (average of 10.5/30 days or 35% of the time period, compared to 21.43/30 days or 71.43% of the time period respectively). These together had minor impact on normal activity (overall average of 11.63/30 days)

Knowledge about condition

Figure 5 shows the average level of knowledge that students have about their condition and how to access support. On average, students with Long COVID have lower levels of knowledge about their condition (4.29 vs. 5.26) and where to access help (3.79 vs. 4.23). Students with Long COVID and Chronic Illness reported similar levels of ability to manage their condition, to ask for help and to explain the impact of it to others compared to those with Chronic Illness. Students were also asked if they were receiving the Disabled Students Allowance. Sixteen (16/39) students with Chronic Illness (41.03%) and 3 out of 14 (21.43%) students with Long COVID were receiving DSA.

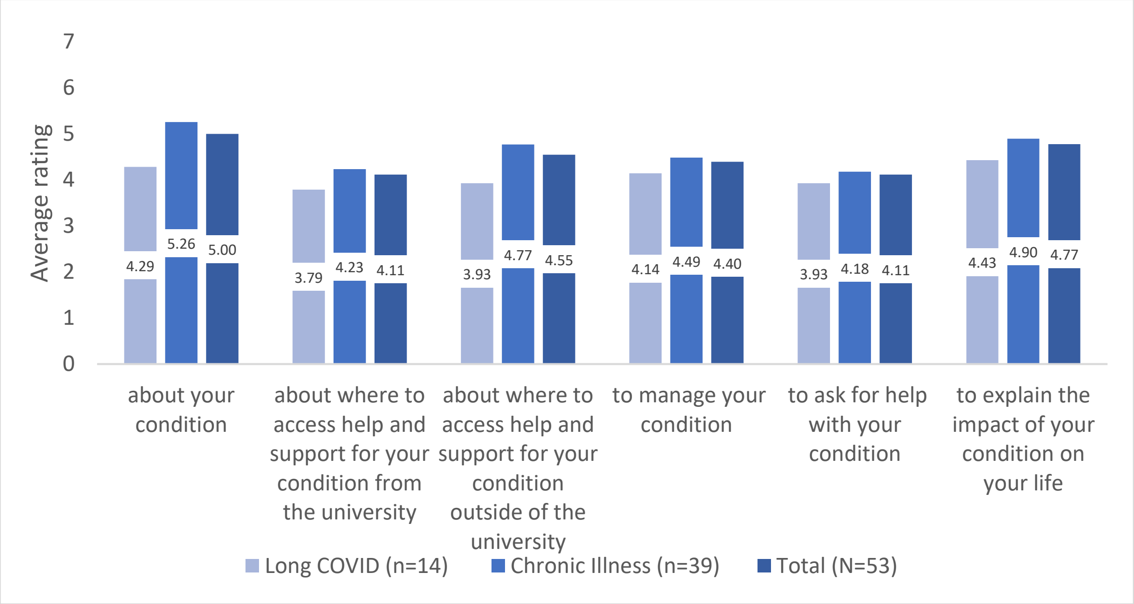

Figure 5: Average ratings of level of knowledge/ability related to their condition (0 = none at all - 7 = very high level of knowledge)

Qualitative data about condition management

Students were also able to complete a free response question, allowing them to comment further on the management of their condition. Seventeen students with Chronic Illness commented on this and answers fell into four themes:

Difficulties with describing their condition to others (2 comments):

> *"It is hard to tell others about my condition without it sounding like an excuse for laziness"* (Student with chronic illness)

> *"With regards to "ability to explain" it is hard to overcome people's preconceptions of just being "a bit tired". Only those who know me very well or have chronic conditions themselves seem to understand the extent to which it impacts me"* (Student with chronic illness)

Challenges with management (10 comments):

> *"As CFS is a very unpredictable condition, it is very difficult to manage. The only medical advice I have been given has been to manage my energy levels, using consistent amounts of energy per day"* (Student with chronic illness)

> *"…It has been difficult to align with the university due to demands on my work and day-to-day which strain and cause my symptoms to become worse and ultimately impacting my studies."* Student with Long COVID

Challenges with accessing support (5 Comments):

"The biggest impact has been the pandemic and safety on placement as a <Department> student. It was a huge challenge to return to placement, the university were initially very unorganised and unhelpful." Student with chronic illness

"I am allowed DSA, but is too complicated." Student with chronic illness

Key Points

- Whilst the profile of symptoms that individual students with a Chronic Illness or Long COVID may experience may vary widely, there are some symptoms that are more common amongst this group, specifically fatigue, energy fluctuations, disturbed sleep and mental health issues

- Students report that generally while their physical health is reasonably good over a 30-day time period, their mental health is more likely to be not good over this time period

- Generally, students are quite knowledgeable about their conditions and where to access help, but sometimes struggle with manage their condition alongside their university work and explaining the impact of their condition to others

Section 2: Support from university-based, department-based and external services

This section focused on contact with university support services, establishing how comfortable students were with that support and how useful that support was once established. Figure 8 shows the average ratings for how comfortable students were with discussing their condition with university academic and support staff.

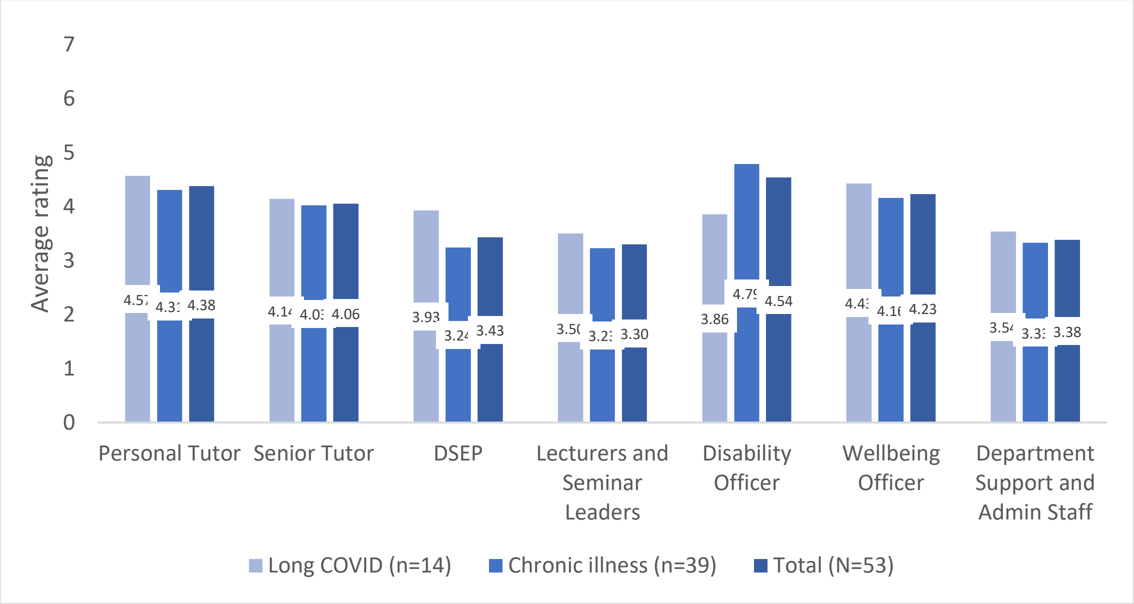

Figure 6: Comfortability in discussion condition (from 1 = extremely comfortable to 7= extremely uncomfortable)

Across both groups, students felt most comfortable discussing their conditions with Disability Officers, Personal Tutors and Wellbeing Officers, and least comfortable discussing with DSEPs, Lecturers/Seminar Leads and Departmental Support Staff. Fewer students with Long COVID were comfortable discussing their condition with disability officers compared to students with Chronic Illness, with 21.43% choosing “7 = extremely comfortable” to “5= somewhat comfortable” compared to 53.85% of students with Chronic Illness choosing these options.

In addition, more students with Chronic Illness were uncomfortable discussing their condition with lecture or seminar leads, with 53.85% choosing “1 = extremely uncomfortable” to “3 = somewhat uncomfortable” compared to 42.86% of students with Long COVID choosing these options. Students also rated the level of support provided by staff in their departments (see Figure 7).

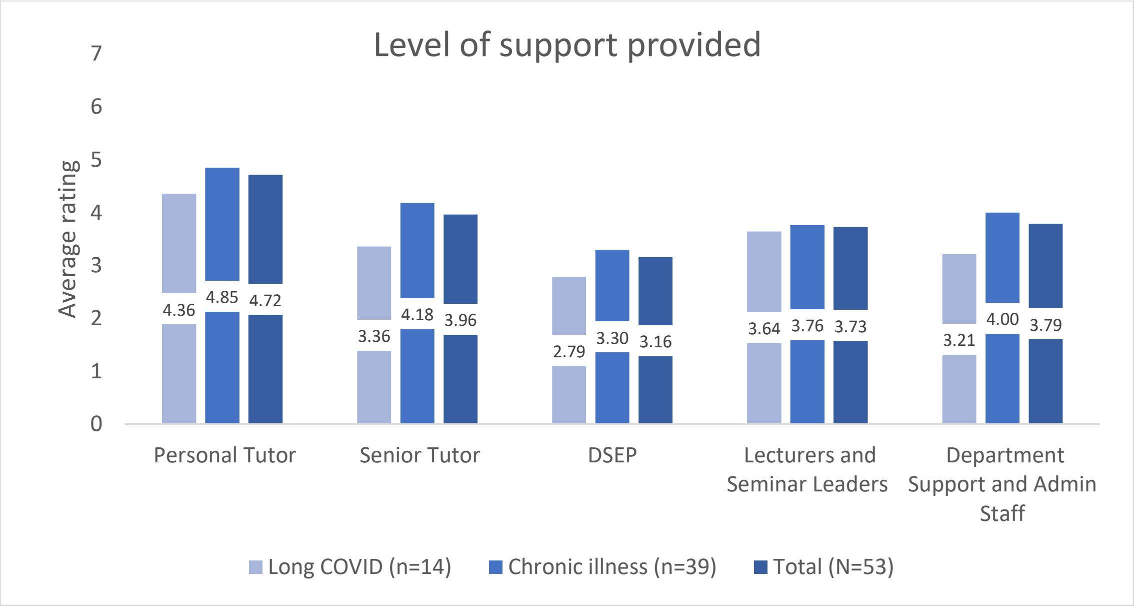

Figure 7: Level of support provided by departmental staff (1 =no support to 7 = very sufficient support)

Average ratings were similar across the group, though slightly lower for students with Long COVID. Students with Chronic Illness were more satisfied with the support provided by Personal Tutors and Senior Tutors[1] compared to those with Long COVID (Personal Tutors: 64.10% vs. 42.86%; Senior Tutors: 51.28% vs. 35.71%). In addition, a higher proportion of students with Long COVID reported the support provided by DSEPs, Lecturers/Seminar Leads and Departmental Support Staff was insufficient or no support was accessed, compared to those with Chronic Illness (DSEPs: 57.14% vs. 41.02%; Lecturers: 42.86% vs. 30.77%; Department Support staff: 50.00% vs. 33.33%).

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[1] i.e. chose options “7=very sufficient support” to “5= slightly sufficient support”)

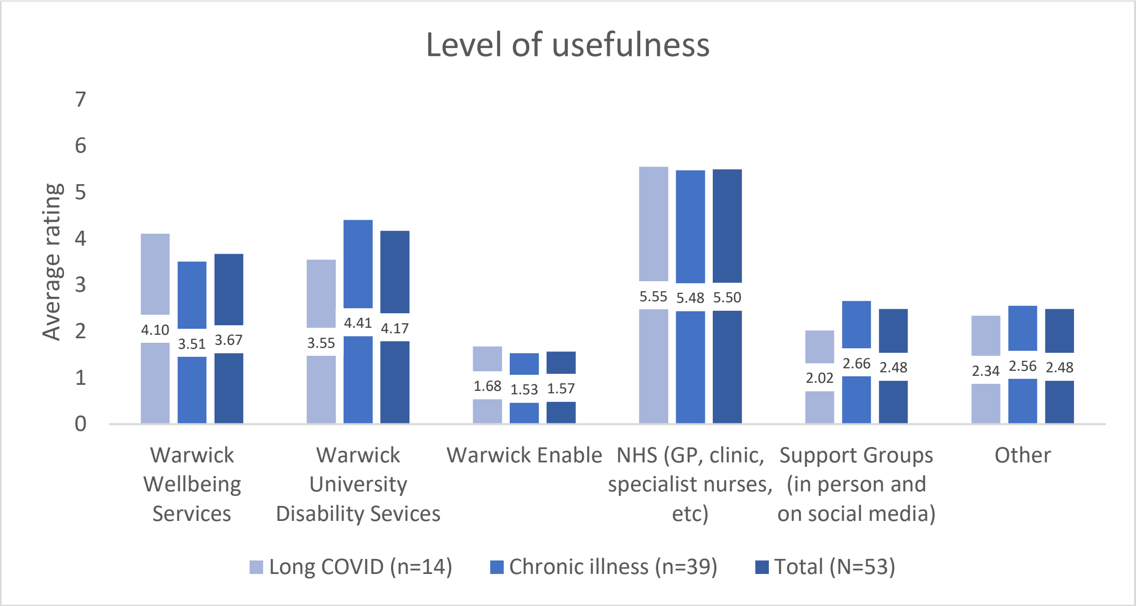

Figure 8: Level of usefulness of different disability support services ("other" included private mental health support, DSA mentors and charities)

Students were also asked about which university-based and external services they found useful (see Figure 8). The most useful were NHS services, Warwick Disability Services and Warwick Wellbeing Services. Contact was at least termly (or more frequent) for NHS services (82.05% students with Chronic Illness, 64.29% of students with Long COVID) and Warwick Disability Services (20.51% students with Chronic Illness, 28.57% of students with Long COVID). Warwick Wellbeing Services were accessed by 20.51% students with Chronic Illness and 28.57% of students with Long COVID. The least accessed service was Warwick Enable and 92.31% of students with Chronic Illness and 71.43% of students with Long COVID reported never having had contact with Warwick Enable (SU society for students with disability).

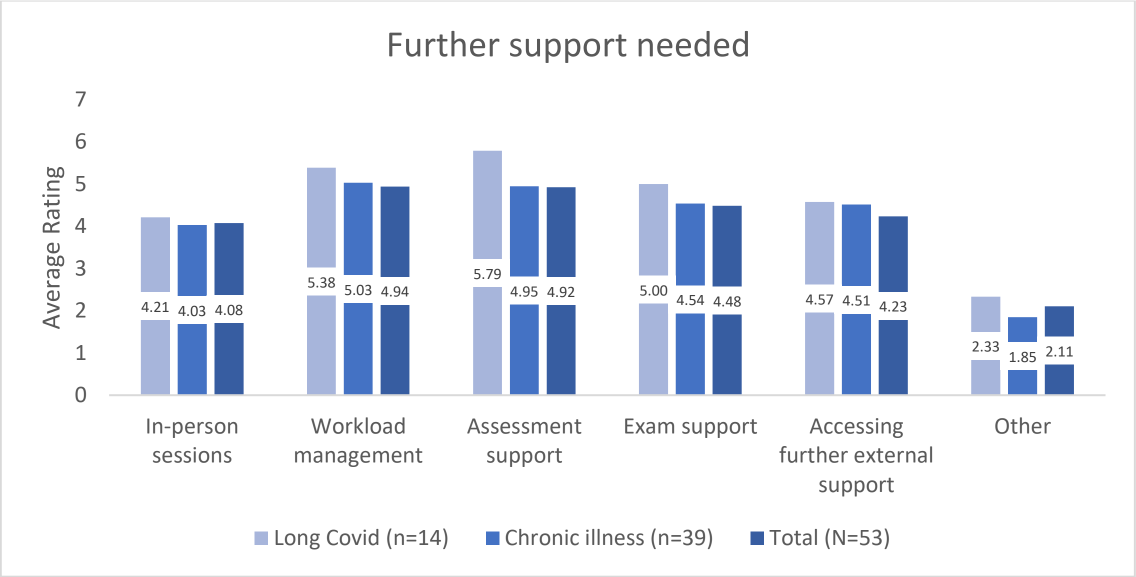

Figure 9: Areas of further support need

In addition, Figure 9 focuses on ratings for how much further support students felt they needed in different areas. Average ratings were similar between those with Long COVID and Chronic Illness, though students reported needing more assessment support. The highest rated areas were workload management, assessment support, and exam support,

Qualitative data: Support needs

Students were also asked to provide further details of the support they have accessed. Seventeen students commented on this question, and comments fell into 5 themes:

Positive experiences with staff (3 comments):

> *"Personal tutor has been very thorough in ensuring support needed at in person lectures was in place from the start of the course, and regularly checks in to determine if this is still suitable."* (Student with Chronic Illness)

> "It's been fantastic to be so understood and supported by staff" (Student with Long COVID)

Mixed experiences (2 comments)

> *"My personal tutor and senior tutors have given me advice and attempted to point me to support, therefore providing as adequate support as they can, however, the support that is offered is inadequate, making the support from these tutors effectively useless."*(Student with Chronic Illness)

> "Only received sufficient support from one seminar leader. Other seminar leaders have not been useful or supportive" (Student with Chronic Illness)

Difficulties with the process (3 comments):

> *"I feel that how comfortable I feel when discussing my conditions with the above departments doesn't really matter as often, in order to receive any kind of support or understanding, it is necessary to discuss my conditions, how they affect me, and what I will need to help with this. Whenever I have tried to speak about my condition in minimal detail (if I have no energy to, feel uncomfortable, feel tired of constantly having to explain myself) I do not receive the same amount of understanding and support"* (Student with Chronic Illness)

> *"I became quite ill during summer 21, and was struggling to keep up with work. I asked for more time to complete an assignment because I knew the effect would be more than a month of difficulty. The answer was a tentative yes, but it was very clear that they did not feel happy offering the extension."* (Student with Chronic Illness)

Support not needed/accessed (3 comments):

> "Plenty of these are inapplicable to me, since they are not provided on my programme." (Student with Chronic Illness)

> *"I have not asked for help or explained my condition."* (Student with Long COVID)

Description of Reasonable Adjustments (5 comments):

"I have been given extra time to complete assignments on more than one occasion." (Student with Chronic Illness)

"Generally I need no support and the support that I occasionally require is in the form of crisis management. This has involved getting extended deadlines, temporary withdrawals and extenuating circumstances for late work and there has been no problems with this." (Student with Chronic Illness*)*

Key points

- Students with Long COVID and chronic illness are most comfortable discussing their conditions with Personal Tutors, Senior Tutors and the Disability Office, and found the support provided useful, though students with chronic illness rated these services higher than students with Long COVID

- Students were least comfortable with discussing their conditions and accessing support from lecturers/seminar leads and departmental admin and support staff.

- Qualitative comments highlighted particular strengths of departmental support, but also issues with communication between departments and Disability Office, and implementation of Reasonable Adjustments

Section 3: Reasonable adjustments

This section focused on use and opinions of Reasonable Adjustments. Ten students (10/14 71.43%) with Long COVID and 33/39 (84.46%) students with Chronic Illness had Reasonable Adjustments in place. These students were asked about their opinions of the adjustments they had been given (see Figure 10).

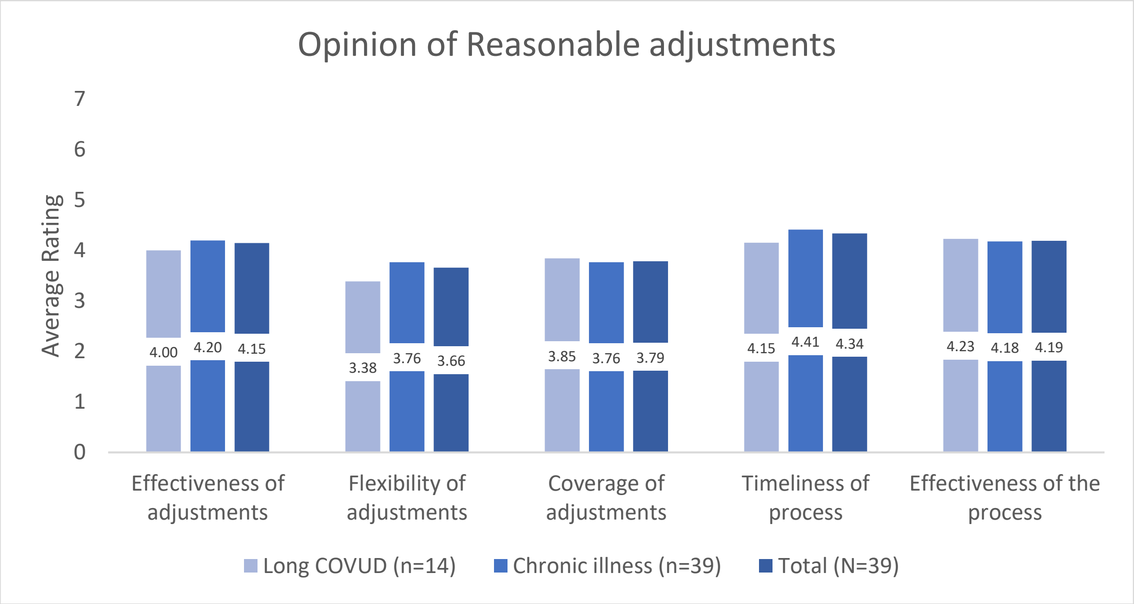

Figure 10: Opinion of Reasonable Adjustments in place (rating scale: 1= not at all, 7= extremely high)

Opinions of Reasonable Adjustments were similar between students with Long COVID and Chronic Illness, with the timeliness (average rating: 4.34), effectiveness of the process (average rating 4.19) and effectiveness of adjustments (average rating: 4.15) receiving highest ratings.

Qualitative data: Reasonable Adjustments

Seventeen students chose to comment further on the adjustments they currently received. These comments fell into 4 themes:

Satisfaction with process (2 comments):

"The system runs smoothly for me" (Student with Chronic Illness)

"Process is timely" (Student with Chronic Illness)

Issues with process (5 comments):

“It is such an arduous process to get adjustments that it has not helped me much at all and has, in fact, added to my workload.” Student with Chronic Illness

“My reasonable adjustments were put in place at the start of my first year. I did not know what was available to me then, and I received information about what they thought would be beneficial for me. I feel the effectiveness of assignment flexibility (deadlines) has been mixed. Sometimes those granting extensions are understanding and do not require additional evidence, whilst I feel others go into reading the request do not fully believe me. I also have no idea how my conditions are taken into consideration when my work is marked - I have been given no information about this and assume it must be a highly subjective decision by the marker. This actually makes me quite uncomfortable, as someone who does not know of or understanding what it is like to live with these conditions is judging to what extent this affected my work, and then marking based on these assumptions. I do not know what kind of information these markers have regarding my conditions and so have no idea how this affects my grade. On multiple occasions when I have requested extensions and decided not to submit evidence of my pre-existing conditions, I have been told that this information of my conditions which I submitted before my first year, is not available to them to grant this extension. I wonder if this information is available for the marker? (Student with Long Covid)

Reasonable adjustments not helpful (6 comments):

> *“The rest breaks are not sufficient to really remedy brain fog and give me an equal chance to think and produce good responses”* Student with Long COVID

> *“Often the adjustments are good but in reality there may be a reason they can't be used... i.e. can't have extension due to external marking or "take breaks from lab when needed" but often not applicable to the actual situation, e.g. I'm running a reaction that needs attention every 15minutes etc. Or I won't finish on time if I have the breaks I need”* Student with Chronic Illness

Concern about department implementation (4 comments):

> *“Teaching staff have denied flexible adjustments for me on multiple occasions”* Student with Chronic Illness

> *“I have to apply in the usual way for an extension for assignment deadlines. It states in the reasonable adjustments that I am not required to provide evidence of my Neuroma however when I had symptoms which were possibly linked to that condition I was still required to provide evidence.”* Student with Chronic Illness

Students were also asked to comment on what adjustments they think they would find useful in the future and why. Responses fell into 4 themes:

Consideration of condition when marking (3 comments):

> *“More visibility to the marker of my work knowing about my disability if I choose - when I hand in work for [Subject] there is no "show disability" function”* Student with Chronic Illness

Allowing more flexibility with different assessment types due to fatigue or other symptoms (5 comments):

> *"Having the option to start an exam later in the day, or take it the next day when feeling better would be much more helpful than a rest break"* Student with Chronic Illness

Provision of mentor/tutors/wellbeing support (2 comments):

> *"one to one mentors/personal tutors who are different from course specific supervisors"* PG student with Chronic Illness

Flexible deadlines without requirement for extra evidence/application (8 comments):

> *"I would find not having to submit evidence of my pre-existing conditions every time I request an extension helpful. This would potentially make me feel less invalidated. Also, as extension guidelines or policies vary across department, I have been unable to get the extensions I have needed from external departments"* Student with Long COVID

Generally, these comments suggest that while Reasonable Adjustments can be helpful for some assignment types, the nature of Chronic Illness means that many adjustments are not effective. There also appears to be inconsistencies with how Reasonable Adjustments are applied across departments. For instance, in some departments, students with flexible deadlines are still required to provide extra evidence in order to get an extension to an assignment deadline. This adds to the difficulty with the process of getting Reasonable Adjustments in place when needed, adding to their workload rather than relieving it.

Key points

- The majority of students do have Reasonable Adjustments in place
- Students are generally satisfied with their Reasonable Adjustments, though some find they are not helpful for their particular issues
- Many students have issues with the application of Reasonable Adjustments within their department, particular flexible deadlines

Section 4: Impact of condition on learning and assessment

Students were asked about how their condition impacted on their ability to access different learning and assessment environments (see Figure 11). For both students with Long COVID and Chronic Illness, access to in-person teaching environments were most affected by their condition, specifically lectures (75.47% reported “moderate” to “very high” impact) and seminars (60.37% reported “moderate” to “very high” impact). Accessing online lectures (22.64% reported “moderate” to “very high” impact) and one to one tutorial (28.30% reported “moderate” to “very high” impact) were least affected.

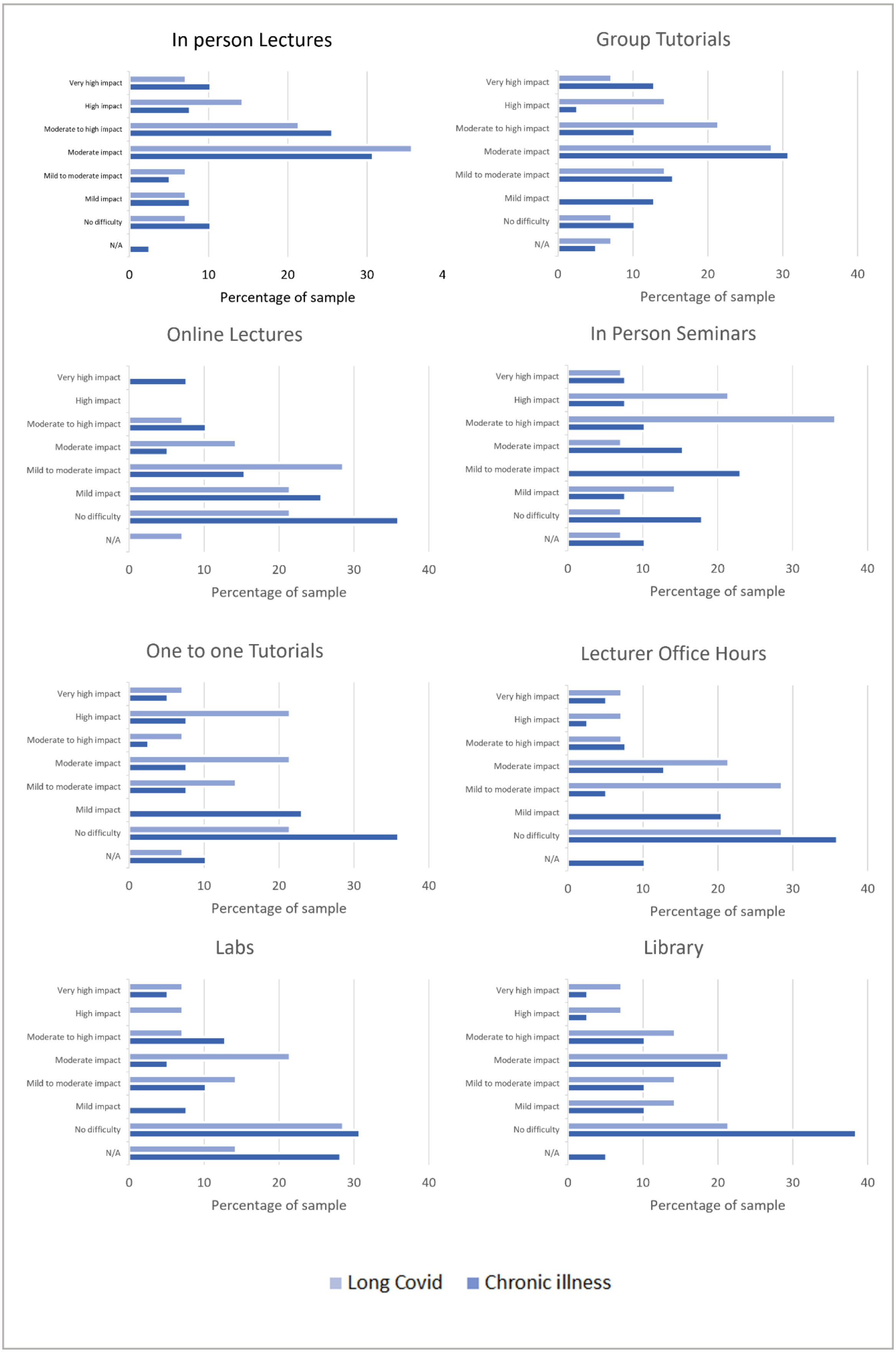

Figure 11: Impact on access to learning and assessment environments

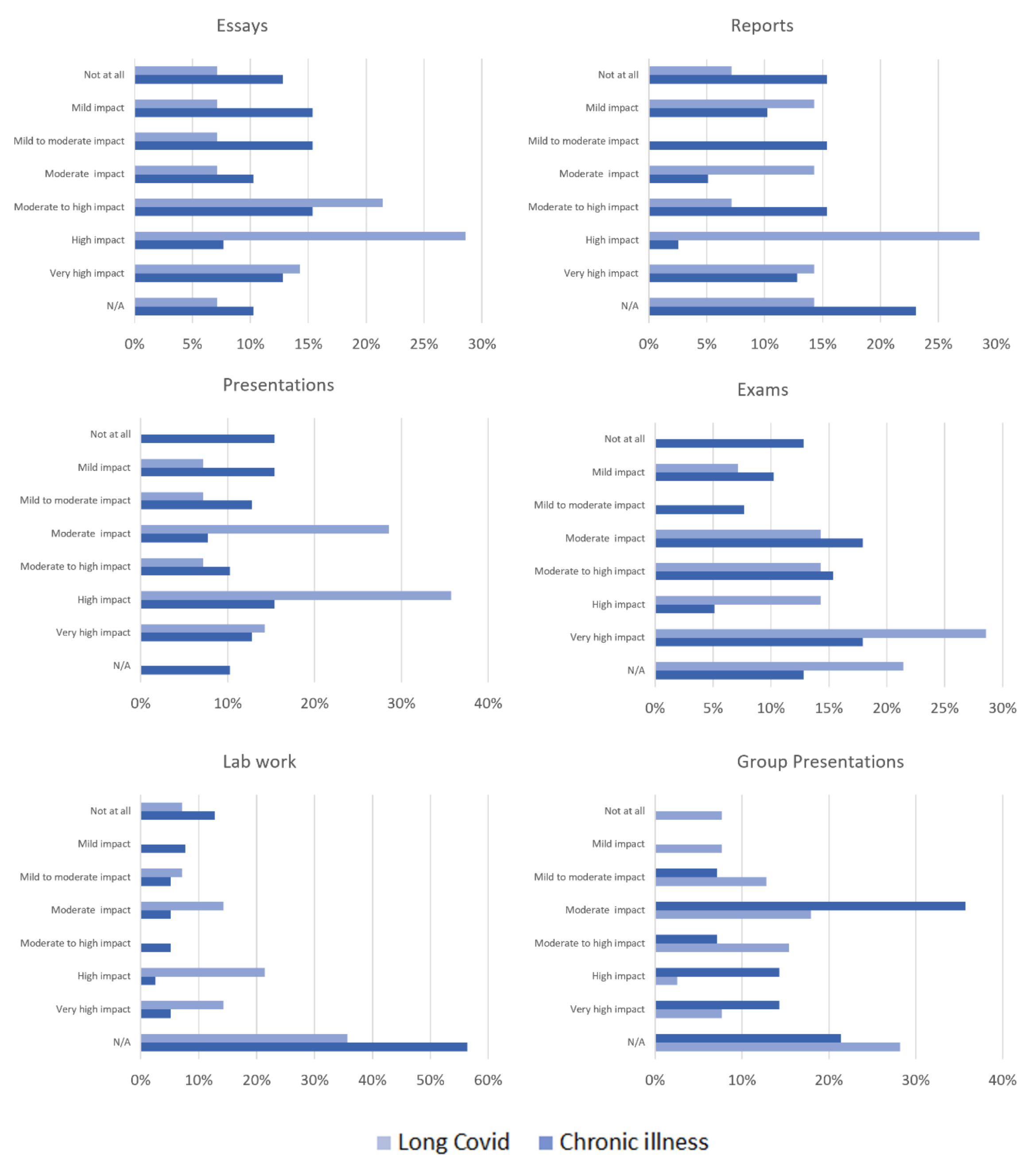

Figure 12: Impact on assessments

Overall students with Long COVID reported a higher impact of their condition on their assessments compared to those with other Chronic Illnesses, particularly for exams (see Figure 12). The knock-on impact of the condition on the grades was also queried (see Figure 13).

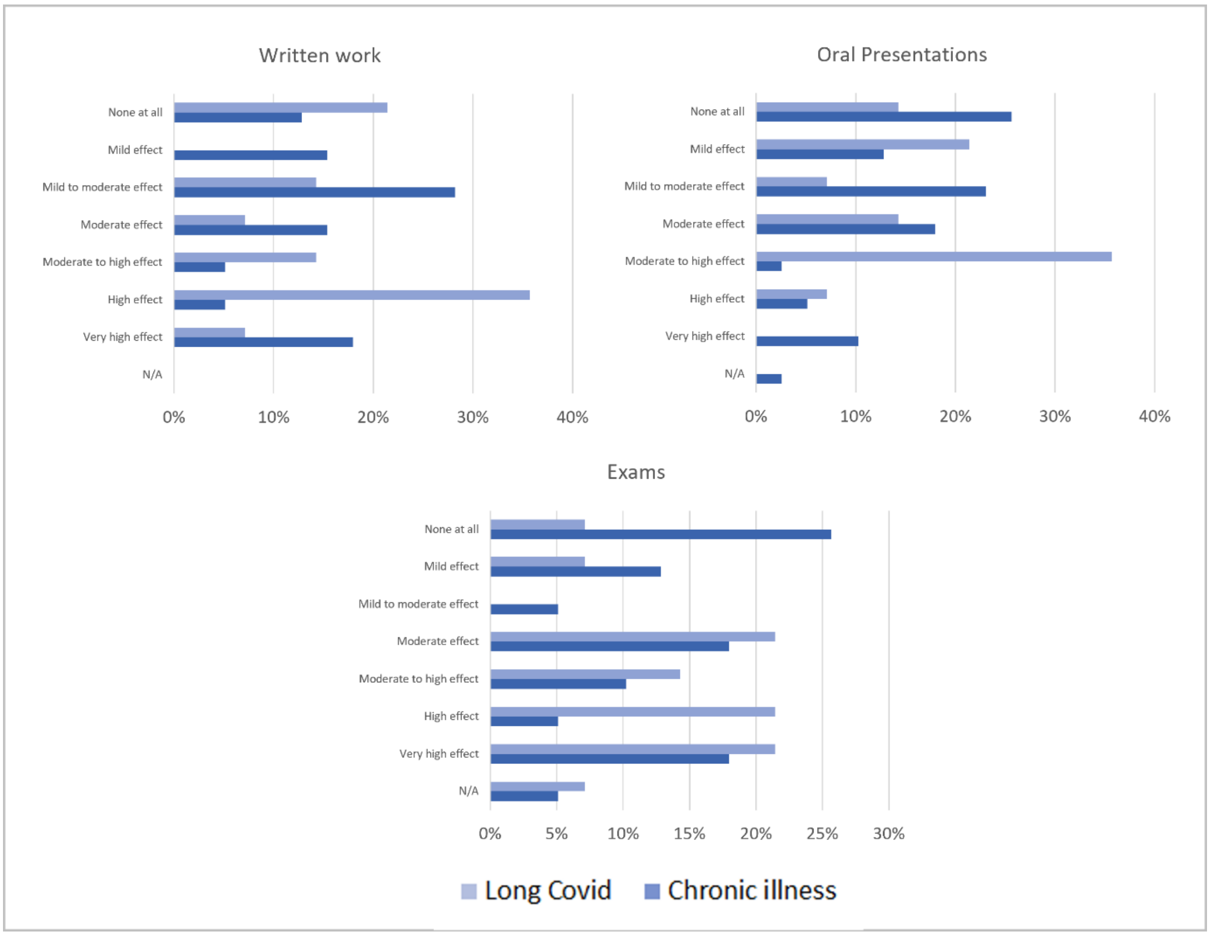

Figure 13: Impact of condition on grades

Qualitative data: Academic Support needs

Students had the opportunity to comment further on their academic support needs. Five themes were identified.

Difficulty Accessing university during "flares":

> *"My illness hits me in waves, usually for one week each month. During these episodes, it is hard to do anything therefore affecting most of these areas."* Student with Chronic Illness

> *"Its difficult to walk to in person things- I much prefer them but having the option for online on days where I have a flare would be good"* Student with Chronic Illness

Missing activities due to fatigue (5 comments):

> *"It is impossible for me to attend anything in person but the use of Teams really helps. This means I have missed all seminars this term."* Student with Long COVID

Difficulties with particular formats:

> *"I sometimes wish lectures were recorded or a transcript was given, since it can sometimes be hard to focus at the time the lecture is being given"* Student with Chronic Illness

Condition specific concerns (4 comments):

> *"Due to the disease I have to carefully plan all travel and this can be difficult with certain lectures/seminars and having continuous access to a bathroom"* Student with Chronic Illness

> *"Difficulty is largest for morning events".* Student with Chronic Illness

Key points

- A high proportion of students reported difficulties with accessing in person teaching environments
- This can be particularly difficult due symptom flare ups, fatigue and at particular times of day.
- Students reported that they do feel their condition affects their ability to complete assessments and exams and does impact on their grades

Section 5: Impact of condition on social and family life

This section explored the impact of the students’ condition on the students’ social life and reliance on others for support (see Figure 14). This revealed a similar level of impact between students with Long COVID and those with Chronic Illness, for most questions. However, “My condition affects my ability to participate in university social activities” and “My condition affects my ability to participate in social activities” received a high amount of agreement (average ratings of 5.73 and 5.81 respectively).

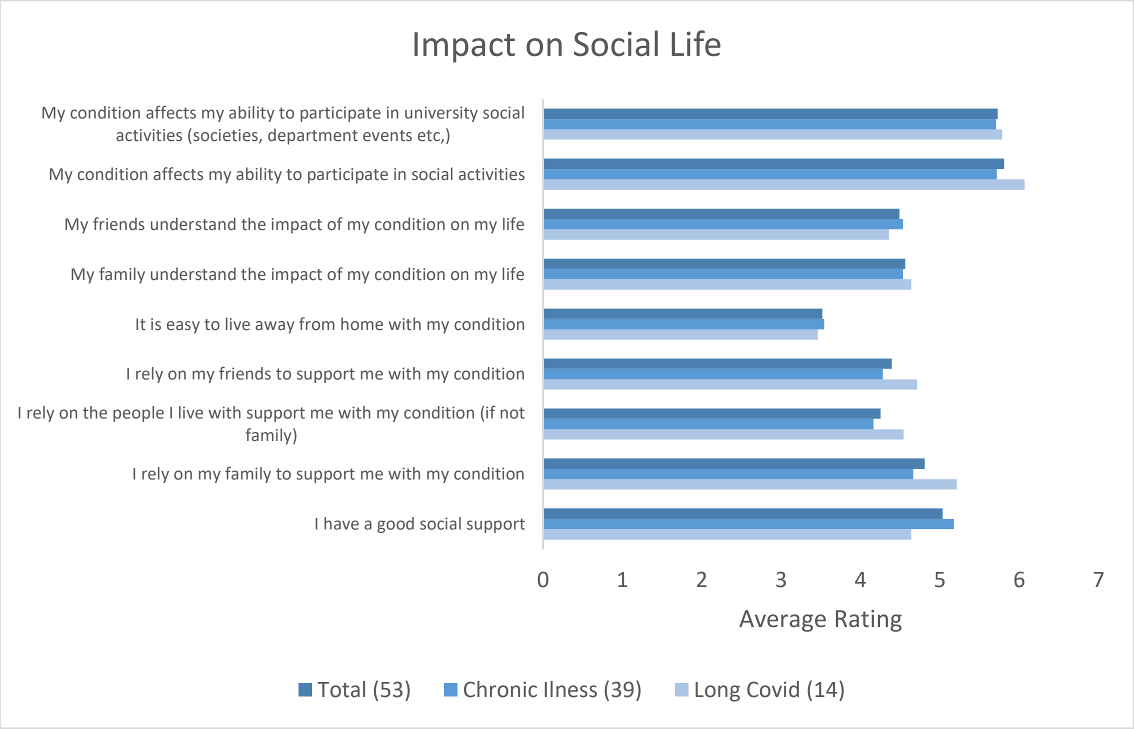

Figure 14: Impact of condition of social life

Qualitative data: Social life

Students were invited to comment on how their conditions affects their ability to participate in social activities. This section of the survey received the greatest number of comments, illustrating the toll that Chronic Illness can have of this part of life. In terms of impact on general social life, 5 themes were identified

Impact of symptoms on social life (12 comments):

> *"I am so extremely fatigued post covid that I spend most of my day asleep. I struggle staying awake and therefore I struggle leaving the house."* Student with Long COVID

> *"Increase gut problems as a result have long covid has caused me more anxiety in social settings."* Student with Long COVID

Impact of mental health on social life (3 comments):

> *"I am a very paranoid person and get very anxious and stressed out in social situations. I often can get overwhelmed or irritable and it is not a relaxing, fun or pleasant experience!"*

Opinions of understanding of family/friends (6 comments):

> *"People can research your condition, empathise, and help make any accommodations which you tell them you need (and obviously this is all really important and makes you feel how much they care) but they don't live with your condition and so don't know your personal limits or needs in that moment. I've found it's very important to communicate this - whether that be they're walking too fast, that you need to take the lift, or you're having a bad day - as long as they listen to these needs is what's ultimately important. I often find that my conditions affect my ability to participate in social activities/situations. My fluctuating energy levels really hinder this, and can often make me feel I am disappointing others or that I'm missing out on important social experiences."* Student with Chronic Illness

Prioritisation of work over social life (2 comments):

> *"With workload, I do not have the energy for any social events. It's either "work" or "play" not both, because it feels for my body, "play" is hard work. Also I get worse when I catch viruses so I often miss things on person as to not get sick and preserve myself"* Student with Chronic illness

Students were also invited to comment on their ability to participate in university organised events, whether that be departmental or via the Students Union. Similarly, to above, the physical (particularly fatigue) and mental health factors were highlighted as restrictions on involvement in university events.

> *"I feel excluded from a great portion of the student population who solely socialise with sports clubs, as it is difficult for me to see myself being in any sports clubs due to my pain, mobility issues and risk of injury"* Student with Chronic illness

Three comments mentioned that events centred on be pub-based or alcohol-focused activities as particularly restrictive.

> *"I don't drink due to the impact on my condition and many events are alcohol dependent"* Student with Chronic illness

Key points

- Social life of students is greatly impacted by their Chronic Illness
- Difficulties stem from both the symptoms of the condition that make socialisation difficult, but also difficulties with the understanding of others about the impact
- Some students feel excluded from SU social events because they are often sports-based or involve alcohol
- Greater awareness of the impact of chronic conditions is needed among student communities

Staff Survey

Staff were asked about their experience supporting students who have a Chronic Illness or Long COVID. Of the 4 staff members who responded, 1 had supported a student with Long COVID, 3 had supported a student with Chronic Illness and 1 had no experience of support a student with Long COVID or Chronic Illness. Staff were asked what information they would find useful when supporting students with a Chronic Illness or Long COVID. Comments focussed on reasonable adjustments and support available at the university:

> *“Sources of support within the university and outside, details of reasonable adjustments available, links to others with the condition and supporting those with the condition”*

> *“The reasonable adjustments for students would be good to know about - in the past, chronic illness has not been supported as well as it might for PGT students; it depended a lot on who their personal tutor was and/or who was on the mitigation panel as to whether something was considered 'serious' or not. But I don't know if things have changed or been updated.”*

They were also asked their opinion on guidance currently provided to staff about Chronic Illness or Long COVID. Two were unaware of any guidance, while 1 reported that:

> *At the moment I am not aware of any specific guidance on how to support students with although there is guidance for chronic illnesses in general.*

Key points

- Engagement with the staff survey was limited, presumable due to the point in term this was carried out (end of Term 3)
- Staff indicated that further guidelines on signposting for students with Chronic Illness and Long COVID would be beneficial
- Guidance on support available and types of Reasonable Adjustments were specifically highlighted

Student Focus groups and interviews.

Focus groups and interviews were broadly focussed on two main themes, namely “Past Experiences” and “Future Recommendations”.

“Past Experiences” aimed to build on the findings of the survey part of the study and deepen understanding of key areas of difficulty that students need support with, specifically i) General support at the university; ii) Management of workload; iii) Social support at the university

“Future Recommendations” focused discussion on i) Resources and improvements, aimed at identifying useful resources and techniques for managing student life alongside a chronic condition and ii) Advice for future students aimed at gathering advice that could be given to newly diagnosed students.

Past Experiences

i. General support at the university

The initial survey addressed general opinions of disability and wellbeing support at the university, therefore the interviews and focus groups attempted to gather more specific information about the process of getting support, and where guidance in this area could be developed further. While some felt the process had worked well for them, others discussed difficulties with the process. For instance, on being asked about wellbeing support, one student said:

> *“I was going to do that but the queue was so long that I just thought I don't have. No, I don't have the energy for this.”* Interview 1, UG student with chronic illness

Others highlighted that the separation between Wellbeing Support Services and Disability Services has been a difficulty:

> *“I thought they were just under one thing, but it's only when I contacted both of them or their departments separately that I realised ohh they don't do the same thing. But I think, like more like liaising between them, might be beneficial.”*

Moreover, some mentioned that Disability Services encouraged them to apply for Disabled Students Allowance, despite having little need for such support, but clarifying that this can be used for support other than equipment or aid may be useful. This may be particularly beneficial for students newly diagnosed – one student with Long COVID said more information about this would be useful:

> *“Putting information there, putting how they just DSA can help and everything so that it's all like centralized, you know acts and then like links to how the disability service can help you.”*

Response of departments to Reasonable Adjustments requirements was a key area for review, because, in both the survey and focus groups/ interviews, there were issues with how Reasonable Adjustments have been implemented . Here, most of the UG students indicated that they had had issues with getting extension for their assignments, even when they were eligible for flexible deadlines or had them in place already:

> *"There have been a lot of times like extension requests are a big issue to me... Most departments I know of require evidence for that. And a lot of the time when, like all the time when I'm submitting an extension request, I'm not well enough to do the assignment, so I'm not one enough to be doing the extension request... And my personal tutor, I don't know where this is true or not, or maybe I'm just remembering, but they said that I don't have to submit evidence again and again and again."* Interview 1, UG Student with Chronic illness

Further comments suggested that getting extensions for assignments may also be variable within the departments:

> *"So it seems to just vary massively depending on who the module lead is and what they're trying to get into it" Focus group, PG* Student with Chronic illness

When asked about the usefulness of their Reasonable Adjustments, most acknowledged the limitations to them, due to the requirements of the course or term structure:

> *"They liked to say they're very restricted on what they're able to do as kind of an excuse to not really do anything. So like I know a lot of the time, like the <redacted> Department are blaming the sort of central uni management and guidelines for restricting them on what they're able to do. But they're also like, there's not enough time and the term like, we can't give you an extension because then it would impact the next thing you've got to do in the next thing you got to do."*

> *"I would say just kind of realizing that they need to structure in periods or people could have a break so that you can catch up on things because I know a lot of people, as soon as you're ill, but even just a few days or a week, you're behind on one deadline and then you're behind on the next deadline and there's never that catch up period and they go straight to the sort of drastic thing of oh, we'll mitigate out that whole piece of work. And I'm like, I would rather be able to do it."*

Others found that while the support from Disability Services had been useful, there was an issue with application of their Reasonable Adjustments within their department:

> “Disability services seems to be very prompt at responding to any queries I have. However, I haven’t had to ask for anything other than reasonable adjustments I have been very disappointed with the lack of support regarding my disability by my own department and have raised complaints to this effect” written communication, UG Student with Chronic illness

There was also some discussion about how that staff and departments can support students with managing their workload:

> *“I mean, my personal tutor is really she's amazing... And she, like there was a period of time. That I did reach out to her and she gave me advice on how to prioritize assignments and stuff.”* Interview 1, UG Student with Chronic illness

> *“I mean, overall, I think my department have been really good and there's a few quite minor specific things and just stuff like the lift quite often doesn't work.”* focus group, PG Student with Chronic illness

ii. Management of workload

Students were asked about how they managed their workload with their condition. Here, students discussed the impact of their condition on completing assignments:

> *“Sometimes I'm just staying in bed all day because I literally can't do anything and it means there's a serious of knock on effect on any work which I can't complete.”* Focus group, PG Student with Chronic illness

They also reflected on what has changed in their approach to assessments and other learning activities as a result of their condition*:*

> *“It was quite apparent how, like everything now takes me a bit longer as a little bit more difficult. Like could be simple things like driving or walking or even if I'm just staying in on my laptop writing, I'll have to occasionally check my blood sugar and make sure I'm eating the right things and so on. So just everything's a little bit more difficult and it is quite clear how like everything just takes me longer now.”* Focus group, PG Student with Chronic illness

In discussion with students, it was evident that planning was important to ensure workload could be managed without burning out.

> *“I have found the workload manageable but have found that I have to take time off occasionally due to pain and fatigue. This does mean I’m hypervigilant when it comes to work and try to get things done as early as possible to avoid missing deadlines.“* Email Interview, UG Student with Chronic illness

Some highlighted the tendency to just try to push through the work and then deal with the inevitable crash later:

> *“It's always been like I've got so good at ignoring being ill now that I can just kind of push out my mind and then it will just come crashing back after the deadlines pass.” Focus group, UG student with* Chronic Illness

Ultimately though, some felt there was little others can do to support this:

> *“The thing is like reaching out for support is. It's a very difficult thing to do to. Especially when I feel like what good can it do if they can't do anything.”* Interview, UG Chronic Illness student with Long COVID

> *There's nothing anyone can do except just do the* work.” Focus group, UG student with Chronic Illness

iii. Social support from university

The survey revealed that students' social life was greatly affected by Chronic Illness. Therefore, the focus groups and interviews explored this issue in more detail to determine what guidance could be offered to students to support this. One such comment outlined the following point:

Future Recommendations

"I think for me it's more sort of the attitude of the department in the they sort of expect you to always prioritize your work over like taking some time for yourself. And I think if they were to sort of shift more to a jobby thoughts of, you know, if you do a 9:00 to 5:00 every day, you should be able to have the weekends or the evenings to relax." Interview, UG Chronic Illness

i) Resources and Improvements

In terms of specific resources that students used, most found it difficult to identify anything specific:

"I don't know really, to be honest. Just kind of I do the work" Focus group, UG student with Chronic Illness

"Yes, but with my conditions, it's very much just energy management is all you can really do" Interview, UG student with Chronic Illness

Instead, students felt that improving staff awareness of Chronic Illness, through lived-experience examples and training would be beneficial:

> *"I feel like a lot of the staff training is very sort of broad and impersonal. And if they had, like, a few people, like case study type things, where they could see like a written first hand account or talk to a person like face to face and actually get an idea of how it really impacts you, then they might be more understanding and like the future in terms of adjustments."*

> *"Having suffered with a disability for years, it has become clear that many people just don't understand and it can be very upsetting. Outreach programmes and education in every department would be really helpful. Potentially part of the 'Warwick values' could incorporate education on disabilities. I am sure that many students and staff living with disability would be more than happy to provide anonymous/non-anonymous information"*

ii) Advice for future students

Students were also asked what advice they would give to others starting at the university or those newly diagnosed. Key pieces of advice centred on encouraging students to access support early, and to be open with staff about the impact of their condition. These suggestions centred around openness (i.e., with university staff) and self-care.

> *"I would say like, as soon as you start out, speak to your senior tutor or whatever and find out everything they can offer you for hypothetical situations and things that you know are likely to go wrong in the future because then you'll feel a lot more calm and how to handle it later on."* Student with Chronic Illness

> *"I will say you definitely have to be open with disability services and speak to them about it. Make sure that you've got your documents from your GP as well, but don't trust disability services to let everyone know. Or rather I should say, don't just trust your department or see when I actually read what disability services say. Make sure you talk to them as well."* Student with Chronic Illness

In addition, students advised self-care and being honest with themselves about how their condition impacts on them and to be accepting of that fact.

> *"I mean, there's like no timeline on When you can expect to feel better which I don't know, It's not entirely hopeful, but it shouldn't mean that you should like keep your life on pause either"* Student with Chronic Illness

> *"Don't isolate yourself because having a disability, it is in itself isolating. (…) So even if it's sending a message to one of your friends or, you know, picking up the phone or I'm not saying like push yourself because you have to listen to your body, but don't lock yourself away because that just makes things worse, like people, care and people are there to support you. You just have to know that you can reach out for that support"* Interview 1, Student with Chronic Illness

Key points

- Issues with accessing support and managing workload are sometimes exacerbated by communication difficulties between staff and with the student
- Many students are constantly vigilant of their physical symptoms to ensure that "flare ups" and burnout do not get in the way of assessed work
- The impact of Chronic Illness can mean that rather than aiming for a work-life balance, which includes socialisation, students have to choose more of a work-rest balance, meaning that the social side of their university experience is limited
- While students concede that university support can only go so far in terms of Reasonable Adjustments and how they fit with the course, more awareness among staff and students and self-acceptance may help manage the impact

Overall Reflections

- **While a new condition, the experience of students with Long COVID has marked similarities with that of students with other Chronic Illnesses, particularly when it comes to accessing support, managing assessments and the social side of university**
- **Many of the students with Chronic Illness and Long COVID in this study were reflective, proactive and conscientious about management their condition on top of their studies**
- **Personal tutors, Senior Tutors and Disability Support staff provide vital support to students who experience these conditions**
- **Areas that require some improvement include communication between staff and students, consistency across departments in how Reasonable Adjustments are applied, and focus on building awareness amongst both staff and students about the impact that Chronic Illness can have on the university experience**
- **When raising awareness of the impact of Chronic Illnesses on student experience it is important to note while there may be similar symptom profiles, Chronic Illnesses and Long COVID affect each person differently, and the impact of the condition is a unique, individual experience**

Next steps…

Having collated the qualitative and qualitative findings we are now developing guidelines for students and staff on managing university life with a chronic condition.

Raising awareness across the university

There were a number of issues reported by students in this study which will be fed back to disability offices and departments, particularly issues with the application of Reasonable Adjustments. In addition, staff training on disability should feature specific content on Chronic Illness. Students also reported feeling excluded from SU events and having little awareness or contact with Warwick Enable (SU society for disability) therefore this will also be fed back to the SU. Finally, the findings of this study have implications for wider student experience policy, therefore the Student Learning Experience & Engagement Committee (SLEEC) will be briefed on the findings of the project

Guidelines for staff

These guidelines provide information on how common symptoms of Chronic Illness affect academic work, based on the findings of our survey, and include anonymised comments from students (provided in interviews etc.) to provide a real-life context to the advice given.

Guidelines for students

Guidelines will be developed separately for students with Chronic Illness and Long COVID. For all students, guidelines will emphasise the individuality of each person’s condition, whilst acknowledging the impact that common symptoms such as fatigue, fluctuating symptoms and sleep issues can have on university life. They will focus on managing academic work, accessing support, and will feature anonymous advice quotes from participants in the study.

Lived-experience video guidance

We are also developing short video featuring a student who has a Chronic Illness discussing his experience studying at Warwick. It will also feature anonymous quotes from participants in the study, with a focus on providing advice and guidance on accessing support.

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