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Cyber-victimisation of adults with long-term conditions in the UK: A cross-sectional study

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Cyber-victimisation of adults with long-term conditions in the UK: A cross-sectional study

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Abstract

Background: Individuals living with chronic conditions and disabilities experience harassment and cyber-victimisation which impose distressing consequences. This is mostly documented among children and adolescents. However, the scope of such experiences is not well-documented among adults with long-term conditions, and the potential impact was not examined from a public health perspective in this context.

Objective: This study aims to examine the scope of cyber-victimisation among adults living with long term conditions in the UK and the perceived impact on the self-management of chronic conditions.

Methods: This paper reports the findings of the quantitative phase of a mixed-method study in the UK. An online survey was developed and disseminated, the recruitment was online via 55 victim support groups, health support organisations, and social media accounts of non-governmental organisations and activists.

Results: Quantitative data from 152 participants showed that almost one in every two adults with chronic conditions was cyber-victimised (45.39%). Most victims (76.81%) had a self-reported disability, and the relationship between cyber-victimisation and disability was statistically significant. The most common means to contact the victims included Facebook (63.24%), followed by personal email or text messaging, each accounting for 27(39.71%). Nine participants (13.24%) were victimised in online health forums. Furthermore, 61.11% of victims reported that experiencing cyber-victimisation had affected their health condition self-management plan. The highest impact was on lifestyle changes such as exercise, diet, avoiding triggers, and avoiding excessive smoking or alcohol drinking. This was followed by changes to medications and follow up with healthcare professionals. The majority of victims (69%) perceived a worsened self-efficacy on the Self-Efficacy for Managing Chronic Diseases Scales. In general, formal support was rated poor, with only 24.53% of victims having disclosed this experience to their physicians.

Conclusions: Cyber-victimisation of people with chronic conditions is prevalent. It triggered significant fear, worsened disability discrimination, and negatively influenced the self-management of different health conditions. Further context-specific and condition-specific research are needed. Clinical Trial: N/A

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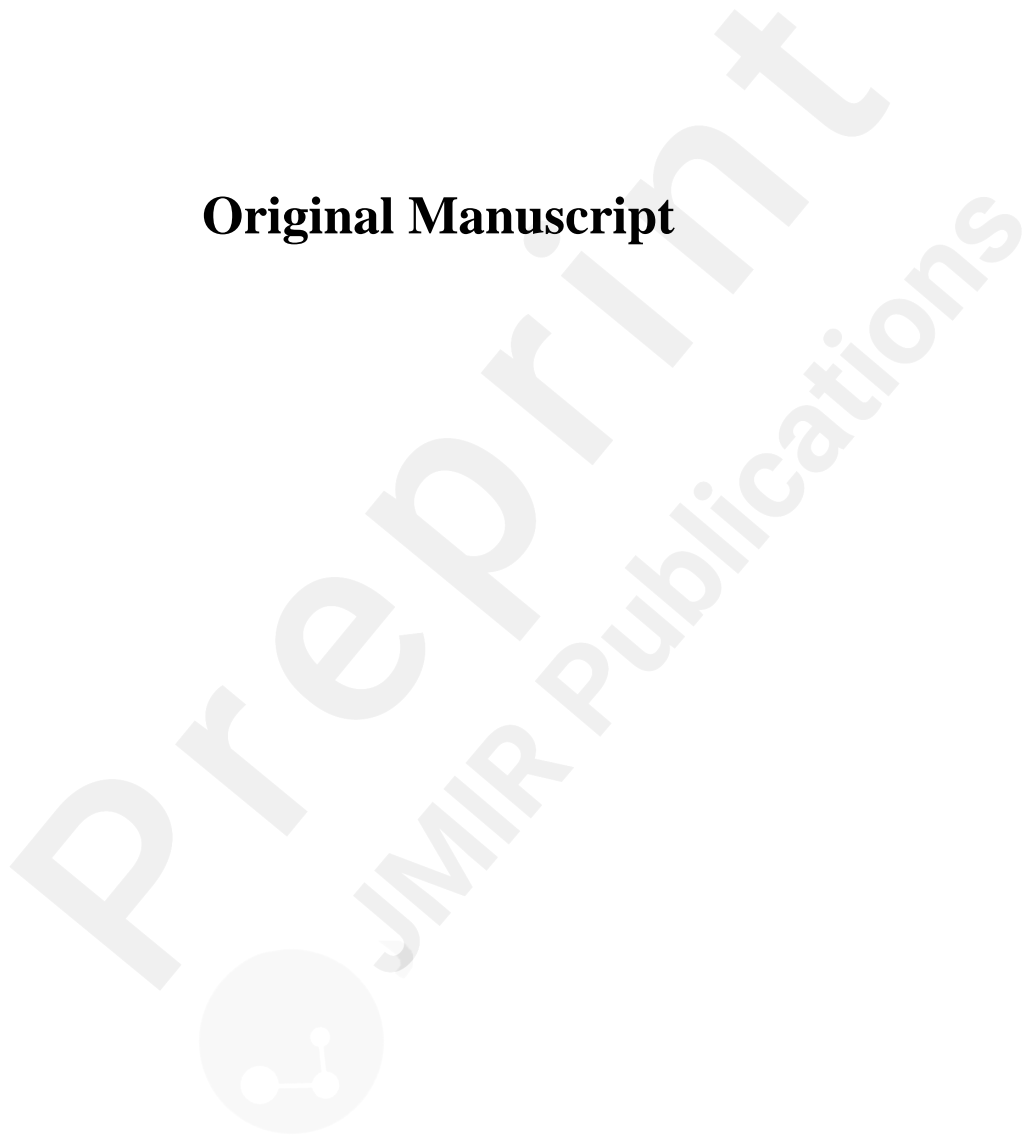
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Cyber-victimisation of adults with long-term conditions in the UK: A cross-sectional study

Abstract

Background: People living with chronic conditions and disabilities experience harassment in both offline and online contexts. Cyber-victimisation is an umbrella term for negative online experiences. It has distressing consequences on physical health, mental wellbeing, and social relationships. These experiences are mostly documented among children and adolescents. However, the scope of such experiences is not well-documented among adults with long-term conditions, and the potential impact has not been examined from a public health perspective.

Objectives: This study aims to examine the scope of cyber-victimisation among adults living with long-term conditions in the UK and the perceived impact on the self-management of chronic conditions.

Methods: This paper reports the findings of the quantitative phase of a mixed-method study in the UK. This is a cross-sectional study that targeted adults aged 18 or over with long-term conditions in the UK. Using an online link, the survey was shared online via 55 victim support groups, health support organisations, and social media accounts of non-governmental organisations and activists, such as journalists and disability campaigners. People with long-term conditions were asked about their health conditions, comorbidities, self-management, negative online experiences, their impact on them, and support sought to mitigate the experiences. The perceived impact of cyber-victimisation was measured using a set of questions on a Likert scale, frequency tables, and the Stanford self-efficacy for managing chronic disease scale. Demographic data and the impact on self-management were cross-tabulated to identify the demographic characteristics of the targeted individuals, potential conditions with complications, and highlight directions for future research.

Results: Data from 152 participants showed that almost one in every two adults with chronic conditions in this sample was cyber-victimised (45.39%). Most victims (76.81%) were disabled, and the relationship between cyber-victimisation and disability was statistically significant. The most common means of contacting the victims included Facebook (63.24%), followed by personal email or text messaging, each accounting for 39.71%. Some participants (13.24%) were victimised in online health forums. Furthermore, 61.11% of victims reported that experiencing cyber-victimisation had affected their health condition self-management plan. The highest impact was on lifestyle changes, such as exercise, diet, avoiding triggers, and avoiding excessive smoking, and alcohol drinking. This was followed by changes to medications and follow-up with healthcare professionals. The majority of victims (69%) perceived a worsened self-efficacy on the self-efficacy for managing chronic diseases scale. Formal support was generally rated poor, with only 24.53% of victims having disclosed this experience to their physicians.

Conclusions: Cyber-victimisation of people with chronic conditions is a public health issue with worrying consequences. This triggered significant fear and negatively influenced the self-management of different health conditions. Further context-specific and condition-specific research is needed. Global collaborations to address inconsistencies in research are recommended.

Keywords: cyberharassment; chronic conditions; disability; social media; cyberbullying; online hate

Introduction

Millions of people worldwide live with chronic health conditions, and the prevalence of such conditions is projected to increase [1]. The term 'chronic' is derived from the Greek word 'khronos',

which means ‘time’, and the dictionary definition for a chronic condition is an illness that persists for a long time or with a recurring nature [2]. In medicine, chronicity covers a group of diseases characterised by recurrence and slow progression. The medical definition of chronicity includes communicable conditions resulting from infectious agents, such as tuberculosis. In public health, and through the lens of international health organisations, ‘chronic disease’ typically refers to non-communicable diseases, which are characterised by a duration of a year or longer, with slow progression and required management that includes medical follow-up and lifestyle changes with or without pharmacological treatment [3]. Examples include cardiovascular diseases, diabetes, cancers, and chronic respiratory diseases including asthma and chronic obstructive pulmonary disease [1, 4]. These represent the leading causes of morbidity and mortality worldwide [1]. The public health definition of chronic disease is the one adopted in this research.

Chronic conditions and disabilities overlap in terms of definition and day-to-day experiences. Hence, a chronic disease can result in disability, and vice versa [5]. For example, 25% of people with chronic conditions have disabilities, and 80-90% of people with disabilities have chronic conditions [6]. The Equality Act 2010 in the UK defines disability as a ‘physical or mental impairment and the impairment has a substantial and long-term adverse effect on [an individual’s] ability to carry out normal day-to-day activities’. A total of 14.6 million people in the UK had a disability in the year 2020-21, which represents 22% of the total population [7]. It is important to distinguish that not all impairments are chronic conditions, and not all chronic conditions are disabling; however, they significantly overlap. The major points in this research are the chronicity factor, which indicates that a person is living with a condition, and the self-management aspect, which reflects the day-to-day changes to lifestyle or medications to manage the condition. To reflect this, from this point onward, the conditions covered in this paper are referred to as ‘long-term conditions’ or ‘chronic conditions’. Disability will be specifically highlighted in questions specific to disability.

Living with a long-term condition is physically and mentally demanding to manage on a daily basis. This is further complicated by being treated differently in society. The ‘offline’ targeting of people with long-term conditions is a documented phenomenon among young individuals [8] and has also been reported as hate incidents against disabled adults [9]. The increase of online communication has further reshaped this phenomenon to include ‘online targeting’, or cyber-victimisation.

A systematic review examined the experiences and impact of cyber-victimisation of people with long-term conditions and disabilities [10]. The narrative synthesis of reported results covered a total of 3,070 people with chronic conditions from ten included studies. The sample sizes ranged from 42 to 823 participants, and the age range was 6–71 years. The reported prevalence range of cyber-victimisation was 2%-41.7% [10]. The risk of being targeted was consistent for people with long-term conditions, which was described as being ‘different’. Such differences might include visible physical differences, invisible neurodiversity or differences in lifestyle management of the health condition, such as using an inhaler or insulin pump in front of peers [11-13]. However, researchers from different disciplines and countries used varied terminologies to address such online incidents.

The terminology related to negative online experiences of people with long-term conditions included cyberbullying, cyberstalking, cyber-harassment, cyber-hate and cyber-victimisation. Cyberbullying is a term used to describe online abuse that involves a power imbalance between the victim and offender; it was the most commonly used term in previous studies [11]. Due to its emphasis on perceived differences in power, cyberbullying is a term used with young victims, such as in schools or in workplaces where the victim has less authority than the perpetrator [10]. Cyberstalking was another term used [14], which is characterised by fixation and persistence. Such persistence can also be seen in cases of cyber-hate and disability hate crimes in which victims had experienced repetitive

harassment from similar groups with a fixation on the impairment [15]. Cyber-victimisation and cyber-harassment were used as generic terms to describe the experience of intimidation or abuse using online communication [12, 14]. Accordingly, due to such differences among researchers and to facilitate communication internationally, the umbrella term 'cyber-victimisation' was adopted in this research.

The reported scope and impact of cyber-victimisation lacks examination of the phenomenon in older age groups. Moreover, limited studies have focused on health consequences. In a cross-sectional study in Sweden [12], a sample of 8,544 individuals was examined, of which 762 individuals were disabled, aged 12, 15 and 17 years. The impact on the victims was mainly subjective health complaints [12]. Another public health study in Sweden [11] looked at 413 participants aged 13–15 years. The reported impact of online experiences included poor health, mental health consequences and self-harm. Both studies [11, 12] provided insight into the impact of cyber-victimisation on health; however, the target population was not adults.

In the United Kingdom (UK), individuals with long-term conditions comprise 30% of the population, 64% of outpatient appointments and 70% of inpatients [16, 17].

No previous research has examined the online experiences of people with long-term conditions in the UK [10]. A relatively recent petition was raised to the House of Commons in the UK with concerns over the cyber-victimisation of people with disabilities. This was followed by investigations, and the governmental report acknowledged the concerns over the cyber-abuse of people with long-term conditions and disabilities. It recommended further legislative and non-legislative acts to prevent such experiences and their long-term impact on health [18]. The research reported in this article was used to inform this governmental report to identify the impact of cyber-victimisation on people with long-term conditions. This study aimed to examine the scope and impact of cyber-victimisation of people with long-term conditions in the UK.

Methods

Ethical approval

Ethical approval was granted by the University Research Ethics Committee at the University of Bedfordshire, UK (IHRREC C557). Ethical considerations were an ongoing process due to the sensitivity of the topic, which also included developing a risk assessment for participants and researchers. The risk assessment included categorising the potential risks arising during the study from low to high, their likelihood, and what was planned to mitigate the risk, such as signposting to support channels, additional discussions with the ethics committee, or a need for disclosure to protect the participants from immediate harm.

Target population

The target population in this survey included individuals aged 18 or over, from any gender, any ethnic background, with a self-reported chronic condition or impairment of a minimum duration of three months, residing in the UK during the research period, and with internet access. The participants were identified as having a long-term condition if they responded 'yes' to the question '*Do you have a long-standing medical condition/illness or disability that requires monitoring, lifestyle changes, and/or taking medications? By long-standing, we mean anything that has affected you over a period of at least 3 months or that is likely to affect you over a period of at least 12 months*'. To ensure that only eligible participants could complete the survey, a pre-screen at the beginning of the survey confirmed the eligibility criteria. Any missing criterion was designed to lead

to a “thank you” note and to ending the survey.

Survey design

The survey questions were developed based on a literature review and discussions with experts in cyber-harassment and were further refined after the piloting stage. The final survey was put online on Qualtrics website using an institutional account. This platform provided sufficient accessibility options for this research. The process of designing the questionnaire online included several tests to check the layout, question designs, and navigation between sections. A further check was conducted to ensure that the results reports reflected the main statistical output expected from each question. When the survey became fully functional, it was used for the piloting stage.

Piloting

The development of tools included a pilot study conducted by the researchers over four weeks, after gaining ethical approval and before commencing the main data collection campaign. The aim of this stage was to test the functionality, clarity, and usability of the online questionnaire and to obtain input from respondents on the wording or other areas of concern. The respondents were approached on the university’s campus and via direct contact with healthcare professionals. The researchers explained to the respondents that the study was a pilot test and invited them to fill out the questionnaire using a “think aloud” approach. The researcher asked the respondents to think loudly while completing the survey to get their real-time feedback on survey questions or use, which helped minimise memorisation issues [1, 2]. After completing the questionnaire, a short interview was conducted with a pre-designed set of questions derived from the literature [3-6]. The set of questions covered the following points: 1) thoughts on time to complete the questionnaire, 2) issues regarding the clarity of instruction, 3) overall layout, 4) confusing questions, 5) objectionable questions, and 6) additional comments to improve the survey.

The number of respondents was 10, representing various demographics in age, gender, ethnicity, and occupation. Four of them reported living with a long-term condition, and two of them went through the experience of cyber-victimisation and provided answers and feedback based on their lived experiences. Respondents who did not have a long-term condition were given the chance to make several attempts at the questionnaire and provide different answers to give feedback on the clarity of questions and layout. The mean time spent filling out the questionnaire was approximately 15 minutes if all sections were answered. The piloting stage influenced the recruitment stage by adding pre-screen questions. This resulted in moving one question to the pre-screen to include only participants with long-term conditions. There were minor issues in skip logic that required technical support from the Qualtrics team. This stage also included changes to the wording and options in six questions (religion, health condition, level of fear and distress, clarification of online harassment, and options of contact by the harassers in two questions). The question on the self-management efficacy scale was understood by the respondents, and the results were in line with the expected statistics from it.

Survey sections

The survey was open to all visitors to the webpage and did not require registration to the website. The survey page started with a pre-screen to confirm three main criteria related to age, living in the UK, and having a long-term condition. This was followed by a briefing consent form. To fill out the

questionnaire, participants had to confirm by ticking boxes that they understood the information given, the anonymity, the right to withdraw, and contact details for further information or to complain. The survey was voluntary, and the participants could skip questions, as highlighted in the consent form, to avoid eliciting distress. Additionally, most questions included 'not applicable' or 'rather no say' as answer choices. The participants were also provided with a back button to check or change answers if needed. A survey logic was implemented to show the participants the options selected in their previous answers, or automatically skip questions not relevant to them. The questions followed this logic without the randomisation of the question. The survey included validation questions to prompt giving a response without forcing it.

The survey had six major sections, each of which included a number of questions. To ensure accessibility, short questions were grouped into one page, and long questions that included matrix buttons or scales were placed on separate pages. The first section focused on demographic information, such as gender, ethnicity, employment, and county of residence. The main outcomes anticipated from this section were the sample description and victims' characteristics. The second section focused on the long-term condition and self-management plan. The participants had to tick their conditions and duration, and were given additional space to add any condition. The plan was to further group the written conditions during analysis according to the nearest medical diagnosis in the 10th version of the International Classification of Diseases for 2015 [7]. Participants with comorbidities were asked about the health condition that affected them most.

The third section was about cyber-victimisation experience; it started with two questions to identify victims. The first question provided the definition of cyber-victimisation in this study and asked participants if they had experienced this. Cyber-victimisation in this research was defined as '*unwanted repeated contact via the internet such as email, chatroom, online forum, social network, mobile phone message, or other electronic means that was used to harass, insult, embarrass, or spread lies about the victim*'. The second question was a direct question about whether they considered themselves victims of online harassment. Fear associated with distress was also included in the third section of the survey because it has been documented that the psychological effects of victimisation have more impact on health [8, 9].

The fourth section explored the participants' coping, self-management during or after the cyber-victimisation experience, and the perceived motivation of harassment [10-12]. The impact of cyber-victimisation on the self-management plan was examined in multiple questions using impact statements, a Likert scale and a self-efficacy scale.

The fifth section was designed to examine the actions taken by the victims and the support received in response to the experience of cyber-victimisation. The last page invited participants to volunteer for the second qualitative phase, which is reported elsewhere (Manuscript 40227).

Using a standardised scale

Self-efficacy is a core concept in the self-management of chronic conditions; it represents patients' own beliefs in how capable they are of taking control of managing their health conditions [13]. Hence, the Stanford standardised efficacy scale was used to examine the perceived impact on the self-management of health [14, 15]. It is formed of six questions to be answered with a score from 0-10, with the average of the six scores representing the self-efficacy of the participant [14].

The researchers aimed to examine the difference in self-efficacy in the self-management of chronic conditions before and after/during the experience of cyber-victimisation. The participants were asked to respond to the set of questions twice, one considering their self-management before cyber-victimisation, and the second considering the current self-management plan. A negative change before and after victimisation could indicate perceived disruption to the self-management plan [16]. The limitations of using the scale are discussed in the limitations section.

Recruitment

Online recruitment was through victim support groups, patient-support groups, and social media accounts of organisations and activists in the fields of cyber abuse or disability campaigners. Search engines were used to look for victim and health support groups. The keywords used included: patient, support, chronic, health forum, disability, hate crime, online support, and specific health conditions' names. The inclusion criteria for gatekeepers included: a) established patient and victim support groups/organisation, b) based in the UK or with a significant audience from the UK, c) having terms and policies in their websites aligning with ethics to protect participants [17], d) having direct contact with patients/victims, and e) provided contact details. Further snowballing was followed to reach relevant organisations, charities, journalists, academics, and activists in the field. The lead researcher contacted 'gatekeepers' via email. When no response was received within 1–2 weeks, an email reminder was sent. In cases where a telephone number was provided, further contact via phone was made. Gatekeepers were provided with information related to the rationale of the study, expected benefits to participants in the short and long term, inclusion criteria, the survey link, study poster, and contact details. Gatekeepers who agreed to collaborate in this research and help in recruitment sent the survey link to potential participants via their mailing lists, social media accounts, and monthly updates.

The recruitment process uncovered challenges in reaching the target population due to the sensitivity of the topic, especially since a considerable number of victims were still experiencing harassment. Four overarching themes influenced the recruitment process: social identity in online support groups, the influencing role of online gatekeepers, the contradictory role of social media, and promoting inclusivity. The challenges and lessons learned from online recruitment in this sensitive topic were theorised using social identity theory and published elsewhere [18].

Data collection process

The average time to finish the survey was 15 minutes; it was longer for participants who completed sections relevant to cybervictimisation. This was consistent between the pilot and main studies. There were daily checks of responses by the researchers to screen IP addresses, filter bots, and remove duplicate responses or false victimisation cases. A separate screening form was developed by the research team in cases of suspicion of false victimisation. False victimisation refers to responses that raise suspicions over being factitious or associated with delusional disorders. The screening tool was used once in this study, and the suspicious response was excluded from the analysis.

The data was anonymised with no means to be traced to the participants' identity, and was stored in accordance with the Data Protection Act 1998. Anonymised data were stored in a password-protected device, and the data were shared only for analysis with the research team. The dataset was not put in an open repository due to the sensitivity of the topic and as another level of reassurance for participants.

Analysis

The survey data were collected over 18 months, from September 2015 to the end of March 2017. Incomplete responses were recorded 48 hours after the participants' last activity. A total of 424 individuals accessed the survey online; 310 of them were eligible based on the pre-screening, with 222 people consenting to participate and 152 participants completing more than 50% of the survey. This is the final number included in the analysis.

The first step in the analysis was to use univariate statistics for descriptive statistics [19]. The participants reported various chronic conditions and/or disabilities. The demographic data were presented, followed by information on the long-term condition. To ensure consistency and accuracy in categorising and reporting these conditions, each response was categorised in accordance with the International Statistical Classification of Diseases and Related Health Problems 10th Revision [7, 20]. Due to variations in terminology used by the participants, each condition entry was checked

manually and cross-checked individually with the ICD-10 classification.

The prevalence of cyber-victimisation in the sample was calculated, and descriptive statistics of the victimisation experience were represented. Fear/distress was presented on a Likert scale, and also grouped into a binary outcome as fear vs. no fear [8]. The number of respondents in this section was variable to allow for skipping questions with which they were not comfortable. Hence, the frequency reflects the number of respondents to a specific question.

The impact of cyber-victimisation was analysed using descriptive statistics and the calculation of the self-management efficacy scale. For each participant, the scale was calculated before and after/during victimisation as described above.

The third step in analysing the survey data was to make cross-tabulations between the independent variables. Cross-tabulation was used to identify different factors in relation to the scope and impact of cyber-victimisation. Statistical significance tests were performed using Stata 12. The main independent variables were gender, ethnicity, age, disability status, and the impact of cyber-victimisation. The statistical significance was measured using the chi-square test to examine the observed versus the expected number of 2×2 tables, with a P value of significance if $p < .05$. The Fischer exact test was used when the number in any cell was less than five [19]. To examine victims' characteristics, cross-tabulations were made to highlight the main characteristics of disabled victims, and to compare them with the whole sample.

Results

Demographics

The sample ($n = 152$) was diverse in gender, ethnic background, and age. Of the participants, 120 (78.95%) were female, 29 (19.08%) were male, and 3 (1.97%) did not specify their gender. The sample included 131 (86.18%) respondents from White ethnic backgrounds, 11 (7.24%) were from Asian ethnicity, 4 (2.63%) had a mixed background, 3 (1.97%) were Black, and 3 (1.97%) were from other/Arab background. The age range of participants was 18 to 65 years, with a mean age of 34.74 (SD = 12.98), and the majority (66; 43.42%) were between 18 and 29 years. However, the age distribution included participants from different age groups: participants aged 30 to 39 years included 33 (21.71%) participants, and those aged 50 years or more were 25 (16.45%). A total of 102 (67.11%) participants considered themselves disabled. At the time of data collection, 128 (84.21%) participants were living in England across 42 counties. The sample also included participants from other parts of the UK; of these, 10 (6.58%) lived in Wales, 9 (5.92%) in Scotland, and 5 (3.29%) in Northern Ireland.

The respondents were asked about their employment. Some participants in this question ticked multiple options and other skipped it. Based on the categories provided in the national guidance [21], the employment status of participants varied: 42 (27.63%) were employed full-time, 42 (27.63%) were students, 22 (21.71%) were unemployed, 12 (8.55%) were employed part-time, 11 (7.24%) were self-employed, and 11 (7.24%) were retired.

The diversity of reported long-term conditions

The participants ($n = 152$) had a wide range of diverse health conditions, with most having multiple comorbidities. Hence, 340 health conditions and comorbidities were collectively reported. Chronic lower respiratory diseases were reported by 53 (34.87%) participants. The second category was endocrine and metabolic diseases reported by 46 (30.26%) participants, and included conditions such as diabetes mellitus, thyroid diseases, and Wilson's disease. Mental and behavioural disorders were reported by 46 (30.26%) participants in the sample. Among these, 4 (2.63%) participants were living with autism spectrum disorder and 3 (1.97%) participants reported Asperger's syndrome. Diseases of the skin—eczema and psoriasis—affected 40 (26.32%) participants. A wide spectrum of nervous

system diseases, such as epilepsy, was reported by 38 (25.00%) participants. Diseases of the musculoskeletal system, such as rheumatoid arthritis, and fibromyalgia, were reported by 36 (23.68%) respondents. This category also includes a range of connective tissue disorders such as hypermobility syndrome, gout, and scoliosis. Diseases of the digestive system, such as non-infective inflammatory bowel diseases, were reported by 24 (15.79%) respondents. Other less common but no less debilitating conditions were reported, such as genitourinary conditions (15; 9.87%), circulatory system disorders (13; 8.55%), congenital malformations or chromosomal abnormalities (10; 5.58%), neoplasms (9; 5.92%), hearing impairments (4; 2.63%), visual impairments (3, 1.97%), and injuries (3; 1.97%).

The experience of living with a long-term condition

The participants (n=152) were asked about the condition that affected them most. The top conditions were diabetes mellitus (23; 15.13%), psoriasis (14; 9.21%), Ehlers Danlos Syndrome (EDS) (10; 6.58%), myalgic encephalomyelitis (ME) (7; 4.61%), anxiety (7; 4.61%), depression (7; 4.61%), asthma (6; 3.94%), fibromyalgia (6; 3.95%), inflammatory bowel disease (6; 3.95%), multiple sclerosis (MS) (5; 3.29%), epilepsy (4; 2.63%), eczema (4; 2.63%), thyroid disease (3; 1.97%), Asperger's Syndrome (3; 1.97%), hypermobility syndrome (3; 1.97%), and renal disease (3; 1.97%). Most participants (136; 89.47%) were diagnosed with one or more long-term conditions by a doctor in the UK.

The management plan of most participants involved multiple aspects; hence, 152 participants shared a total of 999 endorsements of elements of their health management plans. The most common element of health management was related to lifestyle changes, including avoiding triggers that exacerbate illness (93; 61.18%), healthy eating (77; 50.66%), avoiding excessive drinking (66; 43.42%), and physical activity (63; 41.45%). Pharmacological treatment was also reported by most participants, including regular medications (101; 66.45%) and prescription medications (76; 50%).

Cyber-victimisation experience

Cyber-victimisation was found to be prevalent in this sample, as 69 (45.39%) participants were victimised online. The term 'victim' will be used from this point onward to refer to this group for clarity purposes. Due to ethical considerations, responding to questions related to cyber-victimisation was voluntary; hence, the number of respondents in this section varies.

Among the victims (n = 68), the majority (60; 88.24%) reported experiencing fear and distress as a reaction to abusive communication, ranging from extreme fear and distress (22; 32.35%) to moderate fear (24; 35.29%) and slight fear (14; 20.59%).

The duration of the victimisation was more than a year in 25 (36.76%) cases, and between three months and one year in 15 (22.06%) cases. The harassment was ongoing in 17 (25.00%) cases, and 12 (17.65%) victims were not sure whether the harassment had ended.

The most common means of contacting the victims (n=68) included Facebook, as reported by 43 (63.24%) victims, followed by personal email or text messaging, each accounting for 27 (39.71%) of victims as detailed in Table 1. Phone calls were reported by 26 (38.24%) victims. Other means of contact included websites, such as eBay, chatrooms, spam subscriptions, or hacking into friends' accounts. Some participants (9; 13.24%) were victimised in online health forums. Most victims, 67 (98.53%), were contacted once or more per day by their harassers.

Table 1. The means used to contact the victim with frequency and duration (n = 68)

Mean of contact	Once or more per day (n)	More than three times per week (n)	Once per week (n)	Once per month (n)	Less than a month (n)	Total n (%)

Facebook	13	14	4	7	5	43 (63.24%)
Personal email	9	7	4	4	3	27 (39.71%)
Text messaging (such as Whatsapp)	11	6	1	6	3	27 (39.71%)
Phone calls	6	6	5	4	5	26 (38.24%)
Other	8	6	3	2	6	25 (36.76%)
Twitter	9	2	4	3	2	20 (29.41%)
Blogs	5	1	2	1	4	13 (19.18%)
Online health forums	3	2	1	2	1	9 (13.24%)
Work email	2	1	0	2	0	5 (7.35%)
YouTube	0	0	1	2	1	4 (5.88%)
Instagram	1	0	0	1	1	3 (4.41%)
Total	67 (98.53 %)	45 (66.18%)	25 (36.76%)	34 (50.00 %)	31 (45.59%)	

It was reported by 68 victims that 20 (29.41%) harassers were strangers, 14 (20.59%) were identified as acquaintances, and 9 (13.24%) were ex-partners; however, 10 (14.71%) victims were unsure about the identity of their harassers. Additionally, 16 (23.53%) victims specified other categories, such as neighbours, ex-partner's partners, or fellow members of online support groups.

When the victims (n=53) were asked whether they considered having this chronic condition or impairment to be related to the experience of being harassed online, 22 (41.51%) responded 'yes'. These participants were provided with a space to explain their answers, their answers included experiences of disability discrimination, harassers pretending to have the same health condition to get closer to them, or the longer time spent online due to the impairment. This finding was also examined in the qualitative phase of the study (Manuscript 40227).

To find commonalities and differences between the whole sample, all victims, and disabled victims, the characteristics of each of these groups were cross-tabulated and summarised in Table 2. The table shows minimal demographic differences between the sample, participants who experienced victimisation and disabled participants who experienced victimisation.

Table 2. Comparison between the main characteristics of all participants, victims, and disabled victims.

Characteristics	All participants with chronic conditions (n=152)	Victims (n=69)	Disabled victims (n=53)
Demographics			
Gender	Female 120 (78.95%)	Female 56 (81.16%)	Female 43(81.13%)
Ethnic background	White 131(86.18%)	White 61(88.41%)	White 48(90.57%)
Age	Range: 18-65 years Mean 34.74 (SD=	Range: 18-63 years Mean 36.87 (SD=	Range: 18-63 years Mean 37.96 (SD=

	12.98)	12.65)	13.10)
Religion	No religion 74(48.68%)	No religion 38(55.07%)	No religion 8(52.83%)
Employment status	42(27.63%) full time employed, 42(27.63%) students 22(21.71%) unemployed, 12(8.55%) part-time 11(7.24%) self-employed, 11(7.24%) retired	18(26.09%) full time employed, 15(21.74%) students 20(28.99%) unemployed, 5(7.25%) part-time 11(7.24%) self-employed, 4(5.80%) retired	10 (18.87%) full time employed, 12(22.64%) students 19(35.85%) unemployed, 3(5.66%) part-time 5(9.43%) self-employed, 4(7.55%) retired
Professions	41(26.97%) professionals 12(7.89%) service/sales 9(5.92%) clerical support 8(5.26%) managers 6(3.95%) technicians/ associate professionals.	17(24.64%) professionals 7(10.14%) service/sales 1(1.45%) clerical support 5(7.25%) managers 1(1.45%) technicians/ associate professionals.	12(22.64%) professionals 4(7.55%) service/sales 1(1.89%) clerical support 2(3.77%) managers 1(1.89%) technicians/ associate professionals.
Sexual orientation	Straight 113(74.34%) gay/lesbian 10(6.58%) bisexual 12(7.89%) other 8(5.26%) Prefer not to say 9(5.92%)	Straight 51(73.91%) gay/lesbian 5(7.25%) bisexual 7(10.14%) other 3(4.35%) Prefer not to say 3(4.35%)	Straight 39(73.58%) gay/lesbian 4(7.55%) bisexual 7(13.21%) other 1(1.89%) Prefer not to say 2(3.77%)
Cyber-victimisation experience			
Fear/distress	Not applicable	56(81.16%)	46(86.79%)
Means of contact		Facebook 43(63.24%) Online health forums 9(13.2%)	Facebook 34(70.83%) Online health forums 8(16.67%)
Commonest duration		More than a year 25(36.76%)	More than a year 18(37.50%)
Harasser identity		Stranger 20(29.41%)	
Perceived targeting due to health condition or impairment.		22(41.51%)	18(48.65%)

The impact of cyber-victimisation

Among 54 victims, most respondents (33; 61.11%) reported that cyber-victimisation had resulted in an impact on their self-management of chronic conditions. Among these, 32 participants provided more details, they were given their personalised management plan as they shared individually, and were asked to tick the parts of the health management plan that were affected. The majority of changes were under the lifestyle category, such as avoiding triggers that exacerbate illness (19; 59.3%) and healthy eating (12; 37.50%). They also included changes to medications, follow-up with general practitioners (GP), and self-monitoring. A detailed breakdown of the affected aspects of the self-management plan is shown in Table 3.

Table 3. Victims' responses to what specific aspects of the self-management of chronic conditions were affected after cyber-victimisation (n = 32)

Affected aspects of the self-management of chronic conditions	Frequency of endorsements	Percentage of victims (n=32)
Lifestyle changes	60	-
Avoiding particular triggers that exacerbate illness	19	59.38%
Healthy eating	12	37.50%
Avoiding excessive drinking	5	15.63%
Exercise/physical activity	10	31.25%
Avoiding smoking	4	12.50%
Avoiding particular types of food	4	12.50%
Other lifestyle changes	6	18.75%
Pharmacological	16	-
Regular medications	9	28.13%
Medications on need (prescription)	4	12.50%
Medications on need (over the counter)	3	9.38%
Follow up	14	
Regular follow-up with a specialist	2	6.25%
Regular follow-up with GP	5	15.63%
Regular follow-up with other healthcare professionals	2	6.25%
Physiotherapy	0	0
Counselling sessions	5	15.63%
Monitoring	5	-
Self-monitoring at home (example: blood sugar)	3	9.38%
Regular lab tests	2	6.25%
Other	3	-
Alternative/complementary medicine (such as herbal treatment, aromatherapy, acupuncture)	3	9.38%
Other management	0	0
Total	98	-

The impact of cyber-victimisation on the self-management plan was further examined by asking the victims to endorse impact statements that apply to them, which were ranked on a 5-point Likert scale ranging from always to never. A total of 32 victims responded to this question, and their responses reflected multi-level effects on health management and provided potential explanations for the changes stated in Table 3. A detailed breakdown of the impact statements and their endorsements is

reported in Table 4.

Table 4 The endorsements by victims on impact statements that applies to them on a 5-point Likert scale (n = 32).

Statement	Always n (%)	Most of the time n (%)	Sometime s n (%)	Rarely n (%)	Never n (%)
Being harassed made me ignore my medications.	2 (6.25%)	6 (18.75%)	10 (31.25)	6 (18.75%)	8 (25.00%)
I feel that my health never got back to how it was before being harassed.	11 (34.38%)	6 (18.75%)	7 (21.88%)	2 (6.25%)	6 (18.75%)
Being harassed made me too tired to do exercise.	11 (34.38%)	10 (31.25)	7 (21.88%)	1 (3.13%)	3 (9.38%)
Being harassed made me too scared for outside exercise.	14 (43.75%)	8 (25.00%)	8 (25.00%)	1 (3.13%)	1 (3.13%)
Being harassed affected my GP follow-up appointments.	3 (9.38%)	5 (15.63%)	10 (31.25%)	5 (15.63%)	9 (28.13%)
Being harassed made me too scared to attend my appointments.	3 (9.38%)	5 (15.63%)	8 (25.00%)	6 (18.75%)	10 (31.25%)
Being harassed affected my appetite and eating.	7 (21.88%)	12	9 (28.13%)	1 (3.13%)	3 (9.38%)
Being harassed affected my self-monitoring at home.	8 (25.00%)	8 (25.00%)	9 (28.13%)	2 (6.25%)	5 (15.63%)
Being harassed made me take more medications than usual.	9 (28.13%)	6 (18.75%)	7 (21.88%)	5 (15.63%)	5 (15.63%)
Being harassed made me take painkillers more than usual.	8 (25.00%)	4 (12.50%)	10 (31.25)	4 (12.50%)	6 (18.75%)
Being harassed made me take prescribed drugs.	7 (21.88%)	7 (21.88%)	4 (12.50%)	6 (18.75%)	8 (18.75%)
Being harassed made me start smoking or smoking more than usual.	5 (15.63%)	6 (18.75%)	5 (15.63%)	2 (6.25%)	14 (43.75%)
Being harassed made me start drinking alcohol or drinking alcohol excessively.	5 (15.63%)	2 (6.25%)	5 (15.63%)	7 (21.88%)	13 (40.63%)
My treatment was the	15	8	5	0	4

same but I felt worse after being harassed.	(46.88%)	(25.00%)	(15.63%)		(12.50%)
My treatment was the same but my lab tests deteriorated after being harassed.	4 (12.50%)	3 (9.38%)	8 (25.00%)	5 (15.63%)	12 (37.50%)
After being harassed my treatment was the same but my doctor says I am not doing well.	3 (9.38%)	6 (18.75%)	4 (12.50%)	9 (28.13%)	10 (31.25)
After being harassed my treatment was the same but my family/friends think I am not doing well.	6 (18.75%)	10 (31.25)	9 (28.13%)	2 (6.25%)	5 (15.63%)
Other effects	9 (28.13%)	5 (15.63%)	2 (6.25%)	2 (6.25%)	14 (43.75%)

To identify the conditions that were more commonly victimised, these were cross-tabulated with cyber-victimisation. Due to the low number, a statistical significance test was not performed but highlighting these conditions is important for future research. These were mainly people with asthma, diabetes, depression, chronic obstructive pulmonary disease (COPD), anxiety, MS, ME, fibromyalgia, EDS, heart disease, thyroid disease, and IBD.

The results reported above were further cross-checked to identify the impact of cyber-victimisation on each chronic condition reported in the sample, and this impact was shared with the UK government to guide future mitigating actions [22, 23]. Table 5 summarises the impact reported based on the chronic conditions.

Table 5. The impact of cyber-victimisation on the management plan of each reported condition

Category	Reported impact
Endocrine, nutritional and metabolic diseases	
Diabetes Mellitus	<ul style="list-style-type: none"> • Healthy eating (reported by multiple participants in this category). • Avoiding particular triggers that exacerbate illness. (reported by multiple participants in this category). • Monitoring at home (example: blood sugar). • Avoiding particular type of food. • Avoiding smoking. • Avoiding excessive drinking. • Exercise/physical activity. • Regular medications.
Mental and behavioural disorders	

Generalised anxiety disorder (GAD)	<ul style="list-style-type: none"> • Other lifestyle changes, such as: relaxing. • Avoiding particular triggers that exacerbate illness. • Exercise/physical activity.
Depression	<ul style="list-style-type: none"> • Avoiding smoking. • Healthy eating (reported by multiple participants in this category). • Regular follow-up with GP. • Counselling sessions. • Avoiding particular triggers that exacerbate illness. • Regular medications. • Alternative/complementary medicine (such as herbal treatment, aromatherapy, acupuncture). • Avoiding excessive drinking.
Unspecified mental health condition	<ul style="list-style-type: none"> • Healthy eating. • Counselling sessions. • Avoiding particular triggers that exacerbate illness. • Avoiding smoking. • Exercise/physical activity.
Asperger's Syndrome	<ul style="list-style-type: none"> • Avoiding particular triggers that exacerbate illness
Post-traumatic stress disorder (PTSD)	<ul style="list-style-type: none"> • Medications on need (Over the counter) • Regular follow-up with a specialist • Regular follow-up with other healthcare professionals. • Counselling sessions. • Avoiding particular triggers that exacerbate illness. • Other lifestyle changes. • Regular medications.
Bipolar affective disorder	<ul style="list-style-type: none"> • Regular follow-up with other healthcare professionals. • Avoiding particular triggers that exacerbate illness. • Avoiding excessive drinking.
Diseases of the nervous system	
Myalgic encephalomyelitis (ME)	<ul style="list-style-type: none"> • Avoiding particular triggers that exacerbate illness. • Other lifestyle changes. • Avoiding excessive drinking.
Epilepsy	<ul style="list-style-type: none"> • Healthy eating. • Avoiding particular triggers that exacerbate illness. • Medications on need (prescription).
Migraine headache	Healthy eating.

Narcolepsy	<ul style="list-style-type: none"> • Healthy eating. • Self-monitoring at home (example: blood sugar). • Avoiding a particular type of food. • Avoiding particular triggers that exacerbate illness. • Avoiding excessive drinking. • Exercise/physical activity. • Regular medications.
Restless leg syndrome	<ul style="list-style-type: none"> • Regular follow-up with GP. • Avoiding particular triggers that exacerbate illness. • Regular medications.
Diseases of the musculoskeletal system and connective tissue	
Rheumatoid arthritis	<ul style="list-style-type: none"> • Healthy eating. • Medications on need (over the counter). • Alternative/complementary medicine (such as herbal treatment, aromatherapy, acupuncture). • Other management. • Avoiding a particular type of food. • Avoiding particular triggers that exacerbate illness. • Exercise/physical activity. • Other lifestyle changes.
Fibromyalgia	<ul style="list-style-type: none"> • Healthy eating (reported by multiple participants in this category). • Self-monitoring at home (example: blood sugar). • Other management. • Avoiding particular triggers that exacerbate illness. • Other lifestyle changes. • Regular medications (reported by multiple participants in this category). • Medications on need (prescription). • Regular follow-up with GP. • Avoiding a particular type of food. • Medications on need (prescription).
Diseases of the skin and subcutaneous tissue	
Eczema/acne	<ul style="list-style-type: none"> • Healthy eating. • Alternative/complementary medicine (such as herbal treatment, aromatherapy, acupuncture). • Avoiding excessive drinking.

Psoriasis	<ul style="list-style-type: none"> • Exercise/physical activity (reported by multiple participants in this category).
Diseases of the genitourinary system	
Menstrual disorders	<ul style="list-style-type: none"> • Healthy eating. • Regular follow-up with a specialist. • Counselling sessions. • Avoiding particular triggers that exacerbate illness. • Avoiding smoking. • Exercise/physical activity. • Regular medications.
Diseases of the circulatory system	
Heart disease	<ul style="list-style-type: none"> • Regular follow-up with GP (reported by multiple participants in this category). • Avoiding particular triggers that exacerbate illness (reported by multiple participants in this category). • Regular medications.
Congenital malformations, deformations and chromosomal abnormalities	
Ehlers Danlos Syndrome	<ul style="list-style-type: none"> • Medications on need (Over the counter). • Medications on need (prescription). • Alternative/complementary medicine (such as herbal treatment, aromatherapy, acupuncture). • Exercise/physical activity (reported by multiple participants in this category). • Counselling sessions. • Avoiding particular triggers that exacerbate illness (reported by multiple participants in this category). • Other lifestyle changes.

An additional step to measure the impact of cyber-victimisation included using the Stanford self-efficacy for managing chronic disease 6-item scale. The score was calculated for each victim (n = 55) before and after the cyber-victimisation experience; it was negative in 38 (69.09%) responses, positive in 7 (12.73%) cases, and zero in 10 (18.18%) cases. Hence, a negative difference in scale indicates a perceived change in self-efficacy before and after the cyber-victimisation experience and potentially reflects a negative impact of cyber-victimisation on the self-management of chronic

conditions.

The relationship between gender and being cyber-victimised was not statistically significant with a p-value of .61 using the chi-square test. The Fischer exact test was used to examine the relationship between gender and the perceived impact on self-management; however, the result was 1.0, which was not statistically significant.

There was a statistically significant relationship between being a disabled person and cyber-victimisation with a p-value of .23. However, there was no difference in the perceived impact of cyber-victimisation between disabled victims and non-disabled victims. The p-value using the chi-square test was 0.19, which was not significant at $p < .05$.

Sexual orientation and employment status in relation to cyber-victimisation were not statically significant. Reporting fear and distress was statistically significant with regard to the impact of cyber-victimisation, as shown in Table 6.

Table 6 The relationship between fear/distress and perceived cyber-victimisation impact on self-management is statistically significant (n=54)

Fear/distress	Victims who reported cyber-victimisation impact on self-management	Victims who reported no cyber-victimisation impact on self-management	Total
Extreme fear/distress	16	1	17 (31.48%)
Moderate fear/distress	12	6	18 (33.33%)
Slight fear/distress	4	7	11 (20.37%)
No fear/distress	1	7	8 (14.81%)
Total	33 (61.11%)	21 (38.88%)	54 (100%)

The chi-square statistic is 18.82. The p-value is .00. This result is significant at $p < .05$.

The impact of the duration of cyber-victimisation was also examined. The chi-square test was not statistically significant, with a p-value of .20. However, when the categories were narrowed to one year or less compared to more than one year, there was a significant relationship between the duration of cyber-victimisation and its perceived impact. The chi-square statistic was 4.77. The p-value is .029, which is significant at $p < .05$.

Support

The participants sought formal and informal support to cope with the cyber-victimisation experience. Informal support was commoner; among 52 respondents, a total of 37 (71.15%) victims received support from their families. When asked about how helpful it was, family support received variable ratings as: very good (14/37, 37.84%), good (10/37, 27.03%) and poor (11/37, 29.73%). Most victims also received support from their friends (40; 76.92%), which they rated as primarily very good (17/40, 42.50%).

Formal support was less common and the number of respondents varied. It included approaching

victim support groups (20/50, 40%), which were generally rated poor (11/20, 55.00%). Healthcare professionals were also approached (22/52, 42.31%) and this was mainly rated as very good (10/22, 45.45%). The police was contacted by victims (20; 38.46%) and was mainly rated poor (13/20, 65.00%). The support sought by the victims and the perceived effectiveness of the support are detailed in Table 7.

Table 7. Informal and formal support sought by the victims and the perceived effectiveness of the support provided.

Support channel	Yes, approached this channel n (%)	Rating of support received				No, did not approach n (%)	Total responses in this category (n)
		Poor (n)	Fair (n)	Good (n)	Very good (n)		
Family	37(71.15%)	11	2	10	14	15 (28.85%)	52
Friends	40(76.92%)	7	7	9	17	12 (23.08%)	52
Victim support groups	20(40.00%)	11	4	3	2	30 (60.00%)	50
Healthcare professional	22(42.31%)	6	4	2	10	30 (60.00%)	52
Police	20(38.46%)	13	1	3	3	33 (63.26%)	53
Other channels	18(36.73%)	6	2	4	6	31 (63.27%)	49

Discussion

Summary of findings

This cross-sectional study represents the quantitative phase of a mixed-method research to examine the scope of cyber-victimisation experiences among people with long-term conditions and disabilities in the UK, and how it affected their self-managed health plan. Around one in every two people with long-term conditions in this study experienced cyber-victimisation. The sample was diverse in demographics, such as age and ethnic groups, with the majority of participants being female. The participants reported a range of chronic conditions and impairments that were grouped using ICD-10 classifications. The majority of changes to the self-management plan were under the lifestyle category, in addition to changes to medications, follow-up, and self-monitoring. The participants perceived lower self-efficacy, which potentially affected their self-management.

The most common means of contacting the victims was Facebook, and most harassers were strangers. Statistical tests were significant between cyber-victimisation and disability, fear/distress, and the perceived impact of cyber-victimisation on health, long duration of abuse (more than a year), and the perceived impact of cyber-victimisation. Support was sought from formal and informal

support channels, with the former generally rated as poor.

Comparison to prior work

It is challenging to compare the scope of cyber-victimisation among people with long-term conditions with the literature. This is mainly because the prevalence of cyber-victimisation depended on the definition and criteria adopted by the researchers to describe a negative online experience, which varied [8, 24]. This remains an issue. A recent review [25], highlighted the challenges of prevalence inconsistencies in the cyber-victimisation literature due to issues in definitions and methodological variations, in addition to contextual factors, including culture and geographical settings. Among people with chronic conditions, cyber-victimisation was reported to be as high as 41.7% [26]; however, this was in a younger age group and in a different context than this study. It is important to acknowledge cyber-victimisation as a global health issue, and further work is needed to tackle inconsistencies in definitions to have a clearer understanding and facilitate conversations between researchers internationally.

The majority of the participants in this study were females, with no statistically significant difference between the genders. In the current literature, studies that examined the cyber-victimisation phenomenon and its impact on different groups were inconsistent; in some cases, cyber-victimisation was associated with the male gender [27], and in other cases, it was associated with the female gender [28, 29]. Notably, most papers that focused specifically on victimising people with disabilities were male-dominated [30-32], and some studies showed increased cyber-victimisation towards disabled girls [33]. This could be influenced by several factors, such as the young age group in previous studies or focusing on specific disabilities that are commoner among males, such as attention deficit hyperactivity disorder (ADHD). Hence, the current study added to the literature by reporting the experiences of people with long-term conditions with input from women. Further research is needed to examine whether this result reflects attitudes towards participation, higher cyber-victimisation among women, or whether cultural factors have influenced the results, for example, if men are seen as masculinity figures who should not disclose similar experiences.

The participants in this study were all adults aged 18 or over. This is an important addition to the literature. Previous studies on cyber-victimisation have focused on young age groups [24], and how cyber-victimisation affects older populations remains under-research [25]. A review of behalf of the Department for Digital, Culture, Media & Sport examined the evidence on the harms of online experiences on adults, and acknowledged the scarcity of evidence in examining disability hate against adults [34].

Most of the victims in this study were disabled, and there was a statistically significant relationship between cyber-victimisation and being disabled. This is in line with previous research on cyber-harassment and disability [35]), and also research examining cyberbullying among younger age groups [36, 37]. Additionally, almost half of the victims considered victimisation related to their conditions or impairment. One explanation could be the targeting of people with physical impairments by harassers. This is in line with the role of disability discrimination and hate in the literature [35, 38]. It is alarming to see disability discrimination taken to an online context and can potentially lead to cyber incidents or crimes. This study focused on people with long-term conditions, and this significant association that builds on existing literature makes disability and cyber-victimisation a research area to be examined by multidisciplinary teams.

The characteristics of the whole sample and those of the victims with long-term conditions were comparable. The age of the victims was slightly higher in those with disabilities. This finding is unlike the literature that focused on cyberbullying among children [30, 32], showing how the

victimisation continues throughout the life course. Employment status and professionals were less among victims, and less among victims with disabilities. This could be due to restricted physical activity in some physical or invisible impairments [39]. However, this could also reflect accessibility issues, marginalisation, and stereotyping of disabled people [38]. Despite the slight differences, the sample, victims, and disabled victims had comparable characteristics, suggesting an alarming risk of being victimised across all groups.

Most of the victims in this study experienced fear and distress, which is consistent with previous studies [8]. The relationship between fear and cyber-victimisation impact was statistically significant. This perceived impact was also significant in cases with longer durations, which extends the literature and could be used for awareness-raising and health promotion to prevent long-term health consequences. Fear and eliciting distress were factors used in previous studies to examine the impact of cyber-harassment [40], and eliciting distress was also included in defining cyberstalking [8, 41]). Fear can also be viewed as a precursor to harm, which can be physical or mental. Although fear is reported here as an impact because it might influence how the individual manages the chronic condition and results in health consequences, it can also be viewed as a factor to build on for future interventions. For example, fear of safety was one of the factors that facilitated the reporting of cyber-hate cases to the police [42].

The diversity of reported conditions in this research ensured covering different impairments, scoping the impact on each condition, and directing future research. In the literature, only a few of the conditions reported here were reported collectively, and none were specifically reported in relation to victimisation [24]. Asthma was the most frequently reported condition in this study. The impact of victimisation on managing asthma was studied previously among young patients [37, 43]; however, it was not examined at a later age. Diabetes was highly prevalent in the sample, which could reflect its prevalence in the general population and documented victimisation [37]. Patients with thyroid diseases were also victimised; however, this has not been studied before and requires further research. These findings do not exclude people with other conditions; rather, they warn of the increase in cyber-victimisation and the need for research to examine the specific impact on health conditions.

Anxiety and depression were also reported in the sample and were exacerbated by cyber-victimisation, which is concerning, considering the distress caused by the experience itself [8]. Individuals with autism spectrum disorders and Asperger's syndrome were included. However, the impact and victimisation of people with these conditions were less than expected compared to previous studies [31, 32, 44]. This comparison, however, is not conclusive due to the low number of these participants. This could be influenced by the recruitment process and thus requires further research. Such findings reflect the wide range of conditions included; they might also suggest differences in impact compared to younger victims or could be a result of methodological differences.

Invisible conditions, such as multiple sclerosis and myalgic encephalomyelitis were highly reported. The victimisation of people with invisible disabilities has been documented [45] and was further confirmed by this study. Patients with epilepsy also shared the impact of cyber-victimisation on their self-management. Previous studies showed that people with epilepsy were victimised offline [46] or online at a young age [37], confirming that people with conditions documented to be victimised offline, but not studied online or among adults, could be at risk of cyber-victimisation.

Diseases of the musculoskeletal system and connective tissue disorders were reported by the victims, and they require further research concerning cyber-victimisation. EDS is a rare condition in epidemiology [47]. Nonetheless, it was a considerable concern to the participants. The representation of invisible and less common conditions could be linked to the participants' identity and attitudes towards participation [18].

In total, 61.11% of victims reported that experiencing cyber-victimisation affected their self-management plan. Previous research has not specified changes in managing health after victimisation [10, 11, 48]. After cyber-victimisation, the reported impact on self-management was mainly in avoiding triggers, healthy eating, and avoiding exercise. The importance of this lies in the specific aspects of each condition. Lifestyle changes are broad, and the trigger is different in each management plan [49]. Additionally, healthy eating and exercise are essential aspects of self-management, for example, in diabetes, musculoskeletal conditions, and depression. Moreover, triggers of neurological, mental health, and heart conditions can have an immediate effect [50]. Regular medications were also affected. Missing medications, for example, in heart diseases and diabetes, can trigger life-threatening situations [51]. This indicates the need to raise awareness to prevent such serious complications.

In this study, 69.09% of victims perceived a worsened self-efficacy scale for the self-management of health conditions following cyber-victimisation [14]. It is acknowledged that such results do not quantify the impact of cyber-victimisation, and the participants already experienced fear. However, the results reflected the victims' perceptions of how this experience affected their coping. Thus, it could be used as a rough estimate to demonstrate the health disruption caused by cyber-victimisation.

By examining the population at risk of cyber-victimisation, the diversity of the included condition, and the multi-level impact of self-management, it can be argued that cyber-victimisation is a threat to public health. This is in line with previous work that acknowledged that cyber-victimisation results in unexpected health consequences and, in turn, health-associated costs to individuals and systems [25]. Identifying cyber-victimisation as a global health issue is an essential step in an increasingly connected world with massive online communication. During the COVID-19 pandemic, online experiences changed, cyber-victimisation risks increased [52], and more hate crimes were reported in the UK [53-55]. In public health emergencies, and without proper action, people with long-term conditions might face long- and short-term health consequences.

Strengths and limitations

This study has contributed to the body of literature by focusing on adults as an age group and addressing a diverse range of health conditions and impairments. The researchers aimed to give every person living with a chronic condition in the UK the opportunity to participate. However, equal chances for participants in this study were influenced by the recruitment strategy, because gatekeepers were approached in recruitment. The researchers recognise the influence of the recruitment process on the results and do not claim the generalisability of the findings. However, the findings provided an idea of the frequency and inter-relationship between having a chronic condition and, cyber-victimisation experience, and its impact on self-management. Additionally, the recruitment was inclusive of participants facing physical barriers and people who were determined to share their voices, for example, disability rights advocates. The sample in this study is not large; however, the study was specifically designed to examine cyber-victimisation without treating chronic conditions as a homogenous group. Previous studies utilised existing datasets that are not specifically designed for this topic, and chronic conditions were mostly reported in large samples as a homogenous group [24]. Hence, the study design and specific conditions will guide future research.

Using an online approach to reach participants was an inclusive option, given the range of health conditions and the sensitivity of the topic. However, this approach was also challenging. The challenges that faced this study during the recruitment stage were published elsewhere [18]. Lack of internet access and socioeconomic status are also limiting factors to consider [56], as well as social desirability bias in self-reporting [57]. This was managed by designing the survey in a way that more than one question was assigned to address one issue; for example, two questions covered cyber-victimisation experience, and four questions covered the impact on self-management. Additionally,

we encouraged the participants to elaborate on their experiences in the qualitative phase of the study. The self-efficacy scale used was a validated scale. However, the participants were asked about their self-efficacy before and after cyber-victimisation at a single point in time during data collection. Hence, the scores are not conclusive, and they might be influenced by recall bias, or exaggerated in cases of ongoing harassment or mental health impact. This question was used to examine perceived impact, in combination with other questions on the impact of cyber-victimisation, rather than a stand-alone score.

Conclusion and future directions

This study pioneered research on cyber-victimisation of people with long-term conditions in the UK and identified the need to build proper support that is context-specific and condition-specific. Reaching context-specific work could be refined in future research, and a health condition-specific work can be achievable by using these findings to identify possible conditions that were targeted and their potential impact, which could help tailor specific prevention interventions and support by experts in the field. All conditions reported in this study require attention and further investigation due to their potential impact upon victims. It is also essential to tackle inconsistencies in definitions and recognise cyber-victimisation as a global health issue that requires international conversations and consistent language to grasp the scope of the issue and potential interventions. Further research is also needed to examine how public health emergencies in the age of online communication, such as the COVID-19 pandemic, have influenced the online experiences and health outcomes of people with long-term conditions and disabilities. Victimisation of people with chronic health conditions, especially those with disabilities, will continue if we do not take a holistic approach to tackling this pressing issue.

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Conflicts of Interest

None declared.

Abbreviations

Chronic obstructive pulmonary disease (COPD)
Ehlers Danlos Syndrome (EDS)
General practitioners (GP)
Myalgic encephalomyelitis (ME)
Multiple sclerosis (MS)

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Supplementary Files

Completed CHERRIES checklist.

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